

Challenges of Health Care Devolution: Problems of Legitimacy, Consumer Knowledge, and  
Work Transfer in Kansas Medicaid

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## ABSTRACT

The current study is an exploration of Medicaid reform in Kansas, entitled ‘KanCare.’ It address three research questions. (1) What is KanCare and how was it enacted despite the contentious politics around it? (2) How has KanCare affected consumers, or the beneficiaries of Medicaid? (3) How has KanCare affected the provision of health care in Kansas for KanCare consumers? Analysis of interviews with KanCare consumers, health care providers, and policymakers, documents that gave voice to state officials and one consumer advocacy organization, Kansas Health Consumer Coalition, and participant observation revealed three major themes. First, KanCare entailed a contentious legitimization process between its proponents and critics along the issues of a need for change, accountability, and success. By shaping the discourse, advocates helped secure mechanisms of public responsibility that could have a policy feedback effect of further democratizing health policy in Kansas. Second, disparities in consumers’ knowledge of KanCare in relation to the states effort to get the word out about KanCare revealed limitations of the consumer choice model. Third, despite limitations, consumers employed strategies to meet their health needs, while providers did more work to help their patients. Glazer’s term ‘work transfer,’ or a shift in responsibility and effort from paid to unpaid labor, characterizes consumers’ and providers’ stories. There are four theoretical implications of the dissertation. The research contributes to the stress process model of health by advancing personal agency as a factor in mitigating stress due to poverty. It sheds light on how Medicaid consumers make health decisions. The study offers insights into how managed care impacts costs, health outcomes and quality of care by shifting effort to providers. The dissertation uses framing theory and the political process model to understand how advocacy organizations influence policy. Policy

recommendations are made and limitations of the study and suggestions for future research are discussed.

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## PREFACE

In 2013, the state of Kansas implemented KanCare, a series of reforms to restructure the state's Medicaid program. KanCare is a comprehensive overhaul of Medicaid that moved all Medicaid consumers into one of three private managed care plans. Kansas was the first state to do this, with the goals of reducing costs of Medicaid, improving consumers' health outcomes, and bettering the quality of care consumers receive. These three goals would be achieved, the state said, at no cost to consumer care or to provider reimbursements by giving all Medicaid consumers the ability to choose their own health insurance plans. Underlying the creation of the program were emergent ideas by conservative politicians about the virtue of privatizing public programs and the need to foster a greater sense of individual responsibility among their recipients. Reform was needed, and KanCare was the way forward.

Because of my background in political and medical sociology, I took an interest in KanCare, especially after I learned it was to be a nearly complete privatization of Medicaid. For over 20 years, as I learned, states have been changing their Medicaid programs from fee-for-service models to capitated managed care administered largely by the private sector. Medicaid managed care, as it is commonly called, entails contracting some or all of the administration and payment functions of Medicaid, typically to for-profit, private health insurance companies called managed care organizations (MCOs). MCOs use market mechanisms to increase efficiencies, reduce costs, and improve health outcomes and the quality of care. Are these programs effective, and in what ways? Through my graduate work, I learned about critiques of neoliberalism and critiques of liberal welfare regimes that were shifting the responsibility of care from the state to individuals, their families, and markets. These critiques seemed a fitting theoretical framework for analyzing KanCare.

My initial reaction to KanCare was astonishment that the state could just simply tell people to be more responsible for their care, and that would be sufficient to improve their health and quality of care. I was skeptical of policymakers' motivations and goals. Do policymakers base their claims on stereotypes of the poor or people receiving social assistance? Do they assume Medicaid consumers are just lazy individuals who, because of their dependence on government, feel no accountability for their care? What was it policymakers actually expected Medicaid recipients to do that they were not doing already? If they are low-income and poor, what more could they do? Medical sociologists have been clear on how social factors influence health, especially socio-economic status (Link and Phelan 1995). So how does telling people to do more for themselves accomplish anything in that context? The idea of individual responsibility, and the assumption that the poor are not responsible, has always interested me.

It was not quite that simple, I learned. KanCare was also about introducing more choice and competition into Medicaid to facilitate individual responsibility. Competition and choice were the primary market mechanisms by which MCOs would improve the Medicaid experience. Under this new system, Medicaid recipients were called "consumers," emphasizing their role as market actors in the consumption of health care goods and services. As with personal responsibility, I became increasingly curious about how just adding another MCO to the mix and giving Medicaid recipients three plans from which to choose would help people. If more market forces is the way to address Medicaid consumers' needs, then why, in the context of one of the most advanced capitalist economies in the world do Americans rank lower on many health indicators than countries with much smaller private health insurance markets? Would adding a little bit more competition be the solution that consumers need when they face all sorts of obstacles to full participation in society? I was not convinced.



I felt that KanCare was based on claims that seemed out of touch with the realities of poverty that I had been learning about in my graduate coursework. It seemed to me that policymakers had certain ideas for what they thought Medicaid consumers needed, and that KanCare was the answer. I wondered to what extent consumers actually had a voice in the reform. I was told by a former director of Medicaid in Kansas that Medicaid consumers do not always understand what their needs are. I disagree with that assertion and feel that consumers can offer insights into the experience of health in the context of poverty that those living outside poverty may not readily see without imposing their own perspectives and assumptions. It is important to understand how policy intersects with the lived experiences of those whom the policy targets (Chaudry, Brandon, Thompson, Clayton, and Schoeps 2003). Examining constituents' experiences of social programs gives insights into tensions between how programs are supposed to work from the point of view of policymakers and how they work in practice from the perspectives of those whom are to benefit from them. Do consumers, their advocates, and the health care providers who treat them believe that the state is making changes that best reflect the needs and experiences of consumers? Are personal responsibility, choice, and competition what consumers needed, or did they need something else? This was something I wanted to know.

While conducting some preliminary research, I learned from health care consumer advocates in Kansas that KanCare was not without controversy. Consumer advocates were especially concerned that certain groups that have traditionally been left out of managed care would see their benefits cut under KanCare, because some thought the MCOs would put profits before patients, or that the capitation rate would be too low to ensure those with the most complex and expensive health needs received the care they deserved. I wondered if these groups

simply opposed the idea of further privatization as such, which I was not convinced that they were, or was their critique of KanCare something more practical, in the sense that with all the changes, they just wanted to make sure consumers' needs were not ignored. If, as it seemed to me, their concerns were being largely ignored by policymakers, is policymaking in Kansas a relatively undemocratic process? That is, to what extent can publics influence social policy? Sociologists have demonstrated that organized interest groups shape the American welfare state (Quadagno 2004; 2006), and that the politics of social policy have been contentious, but what about Medicaid? Do these groups shape Medicaid policy? More specifically, do consumer advocacy organizations matter in the development of Medicaid? In a society that values democracy, I think it is important to raise questions about how policy is made, and the extent to which policymaking is inclusive of publics, especially when that policy has implications for people's wellbeing and health.

As such, the opposition from advocates piqued my interest. As theoretical models of power suggest, there is contention between groups over what policies should be made, who they benefit, and what ideas prevail and why. From my early observations, Medicaid politics seemed rife with conflict. The state and conservative law makers thought consumers needed KanCare, while consumer advocates and moderate and liberal law makers were either opposed to KanCare or were critical of it. Thus, I saw this as an opportunity to explore how controversial policies are negotiated and implemented in relation to the lives of the people that such policies are intended to help, and what those people thought of the policies. Although it was too early to determine the effects on consumers' health specifically, it was the right moment to observe the politics of health care reform in action in a conservative state and what reform meant for different constituents.

The combination of my interests in the critiques of neoliberalism and the welfare state and the questions I raised about KanCare led to the current study. This dissertation is a case study of the implementation of and responses to KanCare. The focus of the study is health in the context of poverty. As such, my objectives were to gain a better understanding of what Medicaid consumers' needs actually are, and how health policy is made in Kansas. Without a firm grounding in the lived experiences of consumers and a grasp of how policymaking works, I cannot begin to address my deeper concerns over health, poverty, and democracy. Therefore, I raise three questions to explore in this dissertation. (1) What is KanCare and how was it enacted despite the contentious politics around it? (2) How has KanCare affected consumers, or the beneficiaries of Medicaid? (3) How has KanCare affected the provision of health care in Kansas for KanCare consumers?

I use qualitative strategies to explore the intersections of health politics in a state with a comprehensive Medicaid managed care program, and the lived experiences of Medicaid consumers. This exploratory study is based on 22 interviews, document analysis, and participant observation in Kansas. I began my research by attending five public meetings about KanCare, which allowed me to immerse myself, to an extent, in the KanCare world so that I could learn more about it. To understand what consumers need and how KanCare was affecting them, I interviewed seven KanCare consumers. I conducted a content analysis of documents that gave voice to state policymakers and health care consumer advocates and interviewed four Kansas legislators and a state public information officer to gain insights into the politics of Medicaid. Finally, I interviewed ten health care providers, mostly from community health and non-profits, to understand how the implementation of KanCare unfolded. This dissertation reports the results of the study.

Findings raised questions about health care devolution in Kansas Medicaid, specifically problems of KanCare's legitimacy, consumer knowledge and the consumer choice model, and consumers' and providers' experiences of work transfer. The study contributes to the political and medical sociology literatures in three ways. First, the study builds upon the "new politics" of welfare state retrenchment to highlight the role of consumer advocacy organizations in Medicaid and the contentious nature of Medicaid politics in an era of expanding neoliberalism. I conceptualize advocacy organizations as social movement organizations and use a framing and political process model framework to understand how one consumer advocacy group, the Kansas Health Consumer Coalition, influenced KanCare. Second, the research adds to the stress process model of health in medical sociology by underscoring the significance of personal agency as a means to mitigate stressors due to poverty. Third, applying the concept of work transfer to the experiences of the consumers and providers I interviewed demonstrates the analytical rigor of this concept beyond its use for characterizing a shift from paid work of experts in health care to unpaid work of family caregivers. The work transfer concept points to how providers in particular translate policy into practice, which helps us understand how managed care influences costs, health outcomes, and quality of care. Because the study is exploratory, I make no claims of causality or broad generalizations of the findings. Rather, the intent is to raise theoretical questions about the continued marketization of Medicaid and its implications for health politics and for people's health.

Chapter 1 of this study provides the historical and theoretical context for examining Medicaid in Kansas. The review begins with a discussion of Medicaid and the scholarly literature on Medicaid managed care. I situate KanCare in the broader history of health policy in the U.S., focusing on the role of organized interest groups in its development. Inspired by the

“new politics” of welfare state retrenchment, I look to the literature on advocacy organizations in political sociology and their role in health policy and Medicaid. I then place the work of these organizations in the context of neoliberalism, fiscal federalism and delegated governance to set the stage for understanding the historical direction of Medicaid. It concludes with a description of KanCare.

Chapter 2 lays out the method of the research. I explain the research strategy and design. I then discuss how I recruited research participants for interviews, how I selected documents to analyze, and how I analyzed the data. I also present demographic data on the 22 individuals I interviewed and a discussion of my participant observation.

Chapter 3 explores competing claims about the need for reform, accountability, and success of KanCare made by proponents – state officials and conservative lawmakers – and critics of reform – the Kansas Health Consumer Coalition and moderate and liberal legislators- during the legitimization process of KanCare. Though KanCare was enacted despite opposition, a debate on the location of the responsibility for care that emerged suggests that small wins for advocates are possible and could have unintended outcomes in the future.

Chapter 4 explores what consumers knew about KanCare given the state’s effort to disseminate information about the new program during the legitimization process. What consumers said they knew and what they wanted did not mesh well with the consumer choice model touted by the state. Its efforts to get the word out went largely unheard by the consumers I met. Their experiences suggest that what information they did have was confusing or overwhelming, and that they had to work hard just to learn what they did know. Some had positive comments about KanCare, but others were very critical. Otherwise, some consumers were largely uninformed and had few opinions about it.

Chapter 5 explores the experiences of consumers and health care providers in terms of work transfer. Consumers employed strategies to deal with problems of health and poverty that they felt KanCare did little to support. Providers experienced administrative burdens and obstacles to providing care that shifted some of the cost of making KanCare work onto them. Taken together, KanCare defers some of the work of health care from the state to the private realm.

Finally, Chapter 6 synthesizes the analysis from the previous three chapters. I offer an institutional explanation for why KanCare emerged as it did to engender work transfer in terms of a disconnect between policymakers and publics and policy diffusion. I explain how work transfer entails a material and discursive shift in health care, and how the politics of work transfer created an opportunity for advocates to shape the political discourse on responsibility in a way to secure the potential for more inclusive and democratic policymaking in Medicaid in the future. I conclude with policy recommendations, limitations and contributions of the study, and suggestions for future research based on the findings of this dissertation.

## CHAPTER 1

### Theoretical and Historical Context

#### **Introduction**

The purpose of this chapter is to provide the historical and theoretical context for examining KanCare. The chapter begins with a review of the scholarly literature on Medicaid, and how Medicaid managed care affects costs, health outcomes and the quality of care – key problems KanCare was designed to address. The implications of managed care are unclear. What is also unclear is what role organized interest groups have played in the development of Medicaid. The history of American health policy is one of competing organized interests, but how contentious health politics inform policies like KanCare has received little attention by sociologists. The neglect of these organizations is problematic, given the shift in Medicaid from traditional fee-for-service to consumer-centered capitated models of publicly funded health insurance. I look to the new politics of welfare state retrenchment and fiscal federalism and delegated governance literatures for clues. The literature review concludes with a description of KanCare, its stated goals, and main features.

#### **Medicaid**

As a means-tested program, Medicaid was designed to cover a wide range of services to the poor, individuals who largely have a tenuous moral claim for assistance in comparison to seniors receiving Medicare (Starr 2011: 47), but also to low-income persons with medical need (Grogan and Patashnik 2003: 825). It developed as a program oriented toward the “deserving poor” (Tannenbaum 1995: 935) and medically needy with states driving the shape of the program, and not universal health care as progressives envisioned (Grogan and Patashnik 2003).

It reflects an ambivalence about health care for the poor, in that Americans have been unable to reach a consensus on how to include the poor in the health care system (Engel 2006), especially given the level of flexibility states have to determine eligibility levels, benefits beyond what is required by law, or even to have a Medicaid program. Consequently, Medicaid hovers between what Meyer (1994: 10) described as ‘social insurance’ and ‘social assistance.’ It resembles social insurance, as many people consider Medicaid as an “entitlement” that helps historically deserving groups, yet it resembles social assistance with its means test, connection to cash assistance (initially), and restriction to low-income persons who may or may not be “able-bodied.”

Based on a combination of federal and state funding, Medicaid is a state-run health and social care program that provides comprehensive benefits to low-income pregnant women, children, persons with disabilities, and frail elderly receiving long-term care services and supports. Eligibility, benefits, and provider payment rates vary by state, though each state must cover a certain range of services under federal law. “Not only do states vary in how much they spend, but they also vary in the methods used to contain costs, improve access, and ensure quality care” (Miller 2005: 2639). Because of the variety, Medicaid scholars often say, “if you know one state's Medicaid program, you know one state's Medicaid program” (Olson 2010: 5). It is complex, difficult to study without delving into the particulars of each state’s program, but understanding the groups Medicaid serves and the costs associated with it are essential starting points for inquiry.

It is the nation’s largest health insurance program and is vital to many groups (Grogan and Gusmano 2007: 12) covering nearly 68 million, or about one in five, Americans. Forty-five percent of all non-elderly, 70 percent of all children in families, and 40 percent of parents under



the Federal poverty line received Medicaid benefits. The federal poverty line for a family of three in 2013 was \$19,530. Nationally, a little over 40 percent of pregnant women, over 60 percent of people in nursing homes, 20 percent of people on Medicare, and 9.3 million persons with disabilities, including 1.5 million children, were Medicaid recipients in 2013. Over one in three children receives Medicaid benefits, as do over half of children of low-income families. Most people eligible for Medicaid are in families in which at least one family member is employed, meaning it is also a program that helps working families to access health care. Needs also vary along gendered lines, as a slight majority of Medicaid beneficiaries are women (58%). Most states cover pregnant women up to 133 percent of the federal poverty line, with 20 states covering those up to 185 percent (Kaiser Family Foundation 2013). Medicaid generally improves health care access (2013:26), and is therefore essential to the disadvantaged groups it covers. Yet, because of low eligibility levels in many states, Medicaid can be difficult to access unless one earns well below the federal poverty line (Kaiser Family Foundation 2013: 9). In fact, restricting eligibility is one of the main ways states control costs of Medicaid.

Medicaid is also one of the main drivers of health care financing, with many rural hospitals, federally qualified community health centers, and long-term care facilities especially dependent on Medicaid dollars. The federal government covers at least 50 percent of each state's Medicaid costs, depending on the state's per capita income. For states, Medicaid is typically the largest line item in the budget next to public education (Miller 2014: 947). In 2011, Medicaid spending at the federal and state levels combined, excluding administration, was around \$414 billion nationally, with the proportion of costs varying widely according to the needs of eligible groups. A small share of the Medicaid population with very expensive health needs account for a little over half the total cost of the program, and dual eligibles, those who are enrolled in

Medicare and Medicaid, account for nearly 40 percent of the total spending (Naylor, Kurtzman, Miller, Nadash, and Fitzgerald 2015: 533). Children and pregnant women account for two-thirds of the Medicaid population nationally, and of this group, children are the majority, but represent only one-third of the cost, as they tend to be a much healthier population. Although Medicaid spending has increased over the years due to increased enrollment and costs of services, private health insurance premiums, medical care inflation, and national health spending per capita have outpaced increases in Medicaid costs. Two-thirds of Medicaid spending was on acute care, 24 percent went to managed care, 30 percent was on long-term care, and about five percent went to administrative costs. Nearly four percent of Medicaid spending went to safety net hospitals that disproportionately serve the poor and uninsured. Interestingly, because of the government's obligation to cover anyone who is eligible and applies for Medicaid, states cannot cap Medicaid spending (Kaiser Family Foundation 2013), though states like Rhode Island have tried to do so by turning Medicaid into a block grant (Miller 2014). However, Medicaid for children, the State Children's Health Insurance Program created under the Clinton administration, is a block grant program the enrollment and spending for which can be capped. Concerns over costs, along with who is covered, have been two of the driving issues in the shaping of Medicaid.

### **Medicaid Managed Care**

Advanced welfare states have been concerned about controlling costs, improving quality, and expanding access to health care. (Mechanic and McAlpine 2010: S147). The U.S. is no exception, especially with Medicaid. As individual states expanded their Medicaid programs throughout the 1960s into the early 1990s, state policymakers became increasingly concerned with the rising costs of the program and the quality and efficiency of care people received. Contributing to the rising cost of Medicaid, health care costs in general have been escalating

since the 1980s, optional and mandatory Medicaid eligibility expansions have increased the number of people enrolled in Medicaid, and many more Americans today may experience acute poverty at some point in their lives (Sandoval, Rank, and Hirschl 2009: 717). States grossly underestimated these costs, so to remedy cost growth, as well as increase efficiency and improve quality and access, individual states explored outsourcing the administration and delivery of Medicaid to the private sector, or what has come to be called Medicaid managed care (MMC).

Medicaid managed care typically entails either a pre-paid, fixed monthly payment, or a capitation, rate paid to private health plan, or a small fee paid to individual health care providers to manage health care services for a given population. MCOs attempt to drive the cost of Medicaid down. They use a combination of financial incentives to encourage providers to control inefficient utilization of health services and promote preventative care, or they may negotiate lower rates with provider networks, find the cheapest provider of a given service, or shift some of the cost of service delivery back onto providers (Miller and Weissert 2004: 338). MCOs themselves may be paid on a pay-for-performance basis. The movement from fee-for-service to MMC accelerated in the 1990s under the Clinton administration with calls for states to use the waiver process to develop innovative solutions to reduce costs, and improve health outcomes and the quality of care. States in turn sought to increase efficiency, promote more personal responsibility and consumer choice by changing their Medicaid programs from single-payer fee-for-service models delivered completely by the state to capitated MMC models delivered by a combination of state agencies and private sector managed care organizations (MCO) or health maintenance organizations (HMOs) (Friedland 2005: 37; Olson 2010; Pracht 2007: 693).

Medicaid managed care is big business. In all but three states and the Virgin Islands, over 300 managed care organizations provide comprehensive Medicaid benefits, over two-thirds

of which specialize in Medicaid. The majority of Medicaid consumers are enrolled in managed care programs (Hurley 2007: 260), over half of Medicaid consumers are enrolled in for-profit plans, and about 40 percent are enrolled in publicly traded plans (Kaiser Family Foundation 2012: 2). In fact, six Fortune 500 companies cover about one-third of the MMC market (Paradise 2014). With some states expanding their Medicaid programs under the Affordable Care Act, enrollments in MCO plans are likely to grow, along with the market share of those six Fortune 500 MCOs.

Enrollment in MMC programs has typically been voluntary, limited to certain geographic locations, and geared toward pregnant women and children, as they do not normally require complex care, which is the reason why the physically and developmentally disabled and frail elderly have been excluded from managed care (Hurley 2007: 251; Miller and Weissert 2004). In recent years, though, states have increasingly required consumers with greater care needs to enroll in MMC (Kaiser Family Foundation 2012: 1), but those receiving long-term services and supports and dual eligible have often either been left out of managed care, or once they are enrolled, they cannot leave it (Miller and Weissert 2004: 338).

The whole point of MMC is to cut Medicaid costs by increasing efficiency, better coordinating Medicaid services, encouraging primary and preventative care, and reducing duplicative services and unnecessary emergency care (Grogan and Patashnik 2003: 841). Market forces of competition, supply and demand, and financial incentives are supposed to help accomplish these goals. Capitation also forces an MCO to operate under a predetermined dollar amount requiring it to fulfill the obligations of its contract with the state for that amount or less, or otherwise incur the extra costs with no reimbursement. Some state contracts may even have a pay-for-performance measure to ensure contracted MCOs meet their obligations. As of 2013,

payments to managed care organizations accounted for more than 25 percent of total Medicaid spending, and they vary widely from state to state (Paradise 2014). The rate will likely continue to rise as states shift more consumers into managed care plans.

Does Medicaid managed care control costs? Even though cost containment is a goal of managed care, little rigorous current research shows significant cost savings to states with MMC, and results of studies are mixed (Herring and Adams 2011: 448; Kaiser Family Foundation 2012: 4; Caswell and Long 2015: 1). When fee-for-service payment rates were high, states reduced spending, but in states where fee-for-service payments were low, savings were difficult. Miller and Weissert (2004) indicate that evaluation research on managed care plans serving dual eligible indicates that they are more efficient than fee-for-service, but only for Medicare managed care, not Medicaid where capitation payments were higher, except in Arizona where payments were lower. Caswell and Long (2015: 8) found that higher MMC penetration at the county level did not reduce expenditures for non-elderly non-SSI consumers, and they found no consistent evidence of reduced expenditures for SSI consumers. When payments are lower, there is the fear that quality of care declines. State agencies and non-profit health maintenance organizations that have managed Medicaid in many states have been replaced with for-profit health maintenance organizations to improve health and reduce costs. However, evidence shows people tend to have better health outcomes and experience better quality care with non-profit institutions, while for-profits tend to have higher administrative costs than state agencies in the traditional fee-for-service Medicaid systems (Woolhandler and Himmerlstein 2011: 722-723). In Kansas, KanCare was supposed to save \$853 million over five years. There is no data available at the time of this study on whether or not KanCare saved money in relation to what Kansas would have spent otherwise. There is no data to indicate that any change in expenditures was due

to KanCare. It is interesting to note that in the first two years, KanCare MCOs lost money. Amerigroup, Sunflower, and United Healthcare combined lost \$52 million in 2014 and \$116 million in 2013 according to news reports.

Does Medicaid managed care improve health and the quality of care? Increases in MMC never really led to increased primary care physician participation in Medicaid, at least in the late 1990s (Greene, Blustein, and Remler 2005). However, Herring and Adams (2008: 378) found that commercial HMOs increased the likelihood that some physicians in urban markets would accept new Medicaid patients, but that increased likelihood did not translate into increased physician visits or improved access to care (Herring and Adams and 2011: 458). Caswell and Long's (2015: 8) study found no consistent evidence that increased MMC penetration at the county level influences health care access or utilization for non-elderly SSI consumers, but they did find an increased probability that non-elderly non-SSI consumers would visit the emergency room and report difficulty seeing a specialist and unmet need for prescription drugs. Medicaid managed care fails to account for the fact that the poor face complex obstacles and must weigh their actions against the limitations of their milieu. Because of poverty, many Medicaid consumers face structural barriers that contribute to illness and health disparities (Cummings and Braboy Jackson 2008; Link and Phelan 1995; Phelan, Link, and Tehranifar 2010; Read and Gorman 2006). MMC is a 'one size fits all' market-rational model of health care that disregards the constraints that the poor encounter as they engage the health care system (Hill, Zimmerman, and Fox 2002). Interviews with low-income women in Kansas revealed discrepancies between their lives and the assumptions of consumer choice models. Consumer choice presupposes that competitive markets keep prices down and improve efficiency. By increasing people's options, the assumption is that rational consumers will choose the best health care plan for their needs.

The poor already jump through numerous bureaucratic and institutional hoops on a regular basis just to acquire the necessities of life, such as food, utilities, and housing. The rational consumer model presupposed by MMC ignores the fact that the poor typically lack the technical capacity to make well-informed health decisions and instead rely on the expertise of physicians. The cultural hegemony of the medical doctor in the U.S. reinforces this.

Managed care also does not consider other social factors like race and poverty. Perceived racial/ethnic discrimination in receiving health care can also have a negative effect on people's self-reported health, especially for those of low socioeconomic status (D'Anna, Ponce, and Siegel 2010). In addition, there are organizational obstacles. Medicaid consumers can choose different managed care plans, but there is typically only one plan per MCO and usually there are only two or three MCOs. There is a limited network of physicians, especially dentists, and other care providers, since providers are not required to accept Medicaid. This may be more problematic in rural places, though some urban or suburban areas might be underserved, as well. Some providers avoid Medicaid because of the low reimbursement rates relative to private health insurance or leave the Medicaid market altogether because of all the red tape. In effect, consumer choice in Medicaid is a bit misleading and may not really make a marked difference in health outcomes or the quality of care.

The critique of consumer choice in Medicaid managed care posed by Maskovsky (2000) and Hill, Zimmerman and Fox (2002) raises the issue of personal responsibility. States can encourage consumers to be more personally responsible by offering choices in health care provider or managed care plan, promoting primary care over emergency care, or offer incentives to live healthier lives. This is exactly what the Republican Governor's Association argues. A group of medical anthropologists studying managed care reform in New Mexico raised questions

about ‘personal responsibility’ (Lamphere 2005; López 2005; Nelson 2005; Willging 2005). Medicaid managed care “reform has strengthened discourses of patient responsibility and accountability that were probably always present in welfare offices and health care sites but now are supported by a system that seeks more patient responsibility in choosing their health care” (Lamphere 2005: 7). She continues by saying that “patients are asked to take over much of the work of gaining access to the system, enrolling themselves, and finding their way through the bureaucracy so that they can obtain direct services” (2005: 8). This echoes Maskovsky’s claim that managed care, through consumerism, ‘regulates the poor’ akin to how Piven and Cloward (1971) described welfare. It is not just about expecting people to act more rationally and be more accountable, it is about telling consumers what to do with their lives. This notion makes little sense for children, which are the majority of Medicaid consumers, as well as persons with certain intellectual and developmental disabilities and frail elderly in institutional care. Furthermore, making choice is not that simple. As Elbel and Schlesinger (2009: 636) explain, when people are faced with a choice, “[m]ost people have a hard time evaluating multiple dimensions of performance across health plans, and these cognitive constraints become even more pronounced as more plans are considered.” Consumers have difficulty assessing the differences in plans, so they usually rely on simple criteria, like coverage scope and cost-sharing, to choose between plans. In addition, consumers are more likely to just file a grievance with their plan than switch plans if they encounter problems (2009: 637). They found that even among the most empowered consumers, individuals who considered themselves “informed, autonomous, and having options to act,” did not often voice their concerns (40%) or leave their health plan (90%), even when problems were severe (e.g., marked decline in health outcomes, increased out-of-pocket costs)



(2009: 655-57). The point their research makes is that even when consumers are empowered to make choices, they do not often make them, or even act on problems they experience.

According to Hurley (2007), much research has accompanied the development of managed care in Medicaid and even informed state programs, but it has been limited. In their review of the literature, Kaestner, Dubay, and Kenney (2002) find that research is not clear on the effects of managed care on health care utilization. They indicate that most research in this area has been single-state studies with small sample sizes with little explanatory power; and that there is a paucity of research on managed care's impact on health relative to traditional fee-for-service. In the early 1990s, Medicaid managed care programs tended to improve access to quality health care, helped control costs, and increased predictability in the system, but there were restrictions on choice of health care providers (Hurley 2007: 254). These programs tended to be limited in scope and were voluntary, though. Oregon and Tennessee, followed by Rhode Island and Hawaii, led the way with more extensive managed care reforms in the mid-1990s. Large-scale moves from traditional fee-for-service Medicaid programs to capitation-based managed care were problematic for Tennessee but were successful for Rhode Island and Oregon (Hurley 2007: 255). New York, Ohio, and Florida failed to improve their Medicaid systems with managed care. Disappointing financial results drove many commercial managed care companies out of the Medicaid market. In fact, in most states, as later research shows, managed care was not performing to expectations (Hurley 2007: 257), although the impact of the massive shift of Medicaid consumers and many uninsured to managed care in Tennessee (Mirvis, Chang, Hall, Zaar, and Applegate 1995) produced mixed results. Some results were positive (Moreno and Hoag 2001), some were negative, or there was no impact at all on certain health measures (Conover, Rankin, and Sloan 2001). The result was a return to traditional fee-for-service

Medicaid (Chang and Steinberg 2008: 11). Later research, though, suggests that the quality of care under MMC does not often meet high enough expectations and, in some cases, results in substandard medical services (Olson 2010: 158), or no real impact at all (Miller and Weissert 2004). Miller and Weissert (2004: 341) are skeptical that managed care is appropriate for dual eligible groups, as MCOs have little experience or expertise with such highly vulnerable groups who have chronic conditions and limited resources, but the research they cite is from the late 1990s, while Willging (2005) found that managed care reduced resources for mental health safety net providers in New Mexico.

Proponents of Medicaid managed care say that it is supposed to improve health by encouraging preventative care, which is especially important for infant health. There is a surprising lack of research in this area, despite the fact that Medicaid covers one-third of births in the U.S., and that out of 29 countries, the U.S. ranks higher than most on infant mortality, as Kaestner, Dubay, and Kenney (2005: 1816) observe. Their research shows that among white, non-Hispanic women, Medicaid managed care is associated with a two-percent decrease in the number of prenatal care visits, a three to five-percent increase in the incidence of inadequate prenatal care, a significant increase in the incidence of premature births, and no association with the incidence of cesarean section (Kaestner, Dubay, and Kenney 2005). Medicaid managed care, thus, does not generally improve infant health or reduce preventable hospital utilization.

At the same time, some research indicates that there may be positive outcomes of MMC. For example, a comprehensive study of MMC programs in Minnesota, New York, Kentucky, and Vermont showed that, in comparison to those under fee-for-service systems, rural Medicaid beneficiaries in Minnesota benefited from MMC, as they were more likely to have a usual source of care, see a doctor more often, and have fewer emergency room visits. They also found that

persons with disabilities in Minnesota were less likely to utilize specialist care in the previous year, but that may have been due more to access problems than greater efficiency. These case studies found that, if anything, MMC delivered the same level of care but at a lower cost (Coughlin and Long 2004: vii). The MMC programs in Kentucky, New York and Vermont were unsuccessful during the study period.

Nevertheless, despite the wide proliferation of this model, it is not clear if Medicaid managed care actually controls costs or improves health consistently across states (Basu, Friedman, and Burstin 2006; Garrett and Zuckerman 2005; Kansas Health Institute 2012; Sparer 2012; Spitz 2007: 384-385; Thompson 2011: 551; Willging, Waitzkin, and Nicdao 2008). In some states, the effects on health outcomes are modestly positive, in some cases negative, and in others benign. MMC has not returned the cost savings that the MMC rhetoric purports and, in some cases, has resulted in states abandoning managed care projects. Furthermore, it has not had any noticeable impact on the quality of care Medicaid consumers receive. Given this paucity of evidence, it is important to understand why such policies seem to be enacted. Scholars suggest at least two reasons for the diffusion of managed care policies across state Medicaid programs.

Grogan (1997) argued that the trend of moving toward a privatized system of managed care was the product of policymaker attitudes about the deservingness of welfare recipients of public assistance. Policy elites she interviewed claimed there would be increased access and consumers would utilize care more efficiently (1997: 832). Elites also felt it was fair to require consumers enroll in managed care, because people with private insurance were being forced into managed care and that they should not be treated any differently than the average person, i.e., not discriminate (1997: 833). They felt Medicaid consumers acted irresponsibly under the fee-for-service system, and that managed care, through a managed care organization, would hold

individuals more accountable, regulating their behavior. Davidson (1997) is critical of her argument, yet there may be something to it. As Medicaid occupies the thin line between social insurance and social assistance, there may be some residual sentiments about how deserving low-income pregnant women and children are of help, as the Connecticut managed care program only extended to those two groups. While attitudes toward disadvantaged groups might explain some individual decisions, an institutional analysis sheds light on how ideas spread across states over time.

Second, Miller and Banaszak-Holl (2005) take an institutional approach to understanding why states continue to adopt private managed care solutions. After interviewing state and national health policy experts, they determined that the proliferation of a common Medicaid nursing home reimbursement policy is a product of policy diffusion, institutional isomorphism, and rational action. They find that policy ideas spread across states by way of national networks of consultants, experts, and bureaucrats through mechanisms like meetings of the National Association of State Medicaid Directors, the National Governors' Association, and the American Health care Association (2005: 207). In addition, some experts claim that just the fact that some states adopt a certain policy was sufficient cause for their state to do it (2005:208). Still others claimed that state Medicaid programs adopted ideas based on what the federal government did, to "piggyback" on Medicare, for instance (2005: 211).

These two theories shed light on why managed care continues to be the favored way to improve Medicaid, but they also help to understand why Kansas leaders might have chosen the solution they did without defaulting to explanations of political ideology or advancing a political career. While these reasons are plausible, they do not completely explain why certain ideas emerge when they do in the first place and take a certain shape. Attitudes and institutional

mechanisms give insights into decisions made, but not why certain alternatives might not even be available to choose. Empirical evidence does not strongly support reforms of Medicaid that continue the trend of privatization or expand the model to cover *all* Medicaid populations, but they may be popular ideas among elites, especially those that are most likely to gravitate to neoliberal principles. Hence, this is exactly what happened in Kansas in 2013. One issue remains, though. Elite attitudes and policy diffusion might explain why managed care continues to be the favored approach of policymakers, but how these policies actually take shape at the state level is a product of other forces. I look now to the literature on organized interest groups in health politics.

### **Organized Interests in Health Policy**

The American welfare state entails a history of interest group conflict (Skocpol 1993). These conflicts have been more likely to benefit working white men or middle- and upper-class women who were married long-term to a working husband than low income women and racial minorities, especially Black women (Gilens 1995; Herd 2005: 1367; Latimer 2003: 109; Lovell 2002: 192; Meyer 1996: 450; Meyer, Wolf, and Himes 2005). Programs to benefit the poor have been fragmented and scattered at the local level (Piven and Cloward (1971: 46-47), because some believe that such programs encourage poverty (Himmelfarb 1984: 5; Mead 2014; Murray 2014), or that the poor and other disadvantaged groups do not deserve help because of their irresponsibility (Harris 2002). These sentiments were especially prevalent in Southern states (Wexler and Engel 1999: 54). Elites believed that welfare encouraged “immorality, promiscuity, unwed motherhood.” If there was an able-bodied “man in the house,” if she did not keep a “suitable home,” a single mother could lose her eligibility for assistance (Soule and Zylan 1997: 737). Throughout the 1970s and 80s, conservative reformers curtailed welfare (Harvey 2008:

158) and placed more emphasis on the market, personal responsibility (Nelson 2005: 107), and workfare (Peck 2001: 90) for escaping dependency. Over time, groups have tried, and sometimes succeeded, to improve benefits for the poor through social action (Hicks and Swank 1983: 697-98). The same has been true for health policy.

Along with the welfare state in general, the American health care system has a long and contentious history. One of the earliest ideas of some form of national-level health care legislation was a proposal made in Ohio in 1836 that argued for a government-sponsored system of hospitals along major waterways (e.g., the Ohio and Mississippi rivers) and the Great Lakes “for the care of sick and disabled watermen.”<sup>1</sup> Yet it was not until the early twentieth century that health care policy would be on the national political agenda. All along the way, though, groups mobilized opposition to comprehensive national health care reform.

Quadagno (2004: 25) stated, “[p]owerful stakeholder groups . . . have been able to defeat every effort to enact national health insurance across an entire century,” and she argues that “stakeholder mobilization,” or the process by which interested social actors are motivated to political action, has been the primary obstacle to universal health care. Her analysis showed that interest groups compete openly to influence decisions of lawmakers, using various tactics to garner support from stakeholders, in a struggle for how to organize, finance, and deliver health care services and goods. Different stakeholders have played roles of varying significance in health care debates (Quadagno 2011). Furthermore, the American health care system is embedded within a liberal welfare regime that determines its structure, and the institutions of which have been shaped by political struggles between opposing interests and by ideology

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<sup>1</sup> Spencer Research Library, University of Kansas. Proceedings of a Medical Convention of Ohio, and Relative to the necessity for Hospitals on the Western waters and the lakes for the care of sick and disabled watermen. March 24, 1836.

(Quadagno 2010). It is to this struggle between progressive proponents of national health care and those who opposed it that I now turn. I argue this struggle is key to understanding the development of Medicaid and the emergence of KanCare.

In the early twentieth-century, progressive reformers attempted to secure health care access for all Americans. Some states created industrial accident insurance for workers, inspired by similar provisions in Europe (Starr 2011). The Socialist Party went further and proposed compulsory health insurance in 1904 (Starr 2011: 29), after which Theodore Roosevelt's Bull Moose Party campaign for the presidency introduced a national health care plan in 1912 (Quadagno 2006; Starr 2011). Other groups proposed compulsory government-subsidized sick pay for workers, assistance with medical bills and burial expenses, and maternity benefits for low-income workers and their dependents (Starr 2011: 31). These reformers thought that health care benefits was an avenue for reducing poverty and dependency on charity, which in turn benefits the whole society by improving public health and reducing social costs of disease. At the state level, such as in New York in 1919, a successful health care program could have been the 'foot-in-the-door' progressives needed for enacting a national plan, such as was the case with Wisconsin's unemployment insurance program and the universal health insurance plan in Saskatchewan, Canada (2011: 34). However, reformers ran into obstacles.

Different groups opposed compulsory government-sponsored health care benefits. The American Federation of Labor denounced such measures in favor of collective bargaining between unions and employers, a position they soon reversed due to pressure from local labor groups, while women's groups had mixed feeling about it (Starr 2011: 32). Although progressive reformers in the past received support from the American Medical Association (AMA) for public health measures and regulations to prevent quackery (Starr 2011), the AMA opposed progressive

efforts for universal health care, beginning at the local level and eventually trickling up to the national organization. Physicians feared that the government would try to regulate physician fees and the practice of medicine through state health insurance plans (Quadagno 2004: 29) based on capitation instead of fee-for-service (Starr 2011: 33). Meanwhile, the insurance industry opposed progressive measures that included funeral benefits, as they competed with one of their most profitable products: coverage for the costs of a final illness and burial expenses (2011: 33). Finally, with New York's universal proposal supported by labor, women's groups, Democrats and some progressive Republicans, conservative lawmakers there prevented it from reaching a vote. Thus, an interesting commingling of labor, business, women's, physician, and insurance groups and politicians generated roadblocks to national health care. Of particular importance to the fight against progressive reform was the American Medical Association.

Leading the charge against national health reform from the beginning was the American Medical Association (AMA). From pamphlets in physicians' offices (Hoffman 2003), \$2.25 million spent on its "national educational campaign" (Starr 1984: 287), to lobbying Congress, the AMA spread a message of fear of socialized medicine, loss of freedom, and an end to the American way of life. Private health insurance was "the American way," one pamphlet from the 1950s declared. The AMA warned that government bureaucrats taking over American medicine were akin to communist or fascist totalitarianism. Americans should tell their representatives that they "do not want arrogant, expensive, Government meddling in the private health affairs of your family," the AMA said in another 1950s era pamphlet. Health was an issue for individuals, their doctors, and their health insurance companies according to the AMA, not government. "Powerful special interests [like the AMA] . . . used every weapon on hand to keep the financing of health services a private endeavor" (Quadagno 2006: 205). Government would only make things worse.



The AMA succeeded in their opposition largely because their objectives paralleled those of insurance companies and, surprisingly, some labor unions (Quadagno 2004: 30). Insurance agents, dentists, druggists, and scores of other national and grassroots groups opposed “compulsory” health insurance in favor of private health insurance that companies were offering at the time. In addition, the American Federation of Labor and the Congress of Industrial Workers believed that health care was part of a fringe benefits package workers and employers negotiated privately. They did not want the state involved, though their sentiments changed over time. One problem was that collectively bargained health plans did not include retirees, a problem progressives would take up later.

Shifting political priorities and changing economic conditions during the Depression years moved reformers to consider ideas that were more comprehensive and national in scope. Medical costs had begun to climb, which affected more than just lower-income workers but the middle class as well. Thus, public forms of health insurance became the goal of reformers, not just specific benefits. Moreover, reformers turned from state-level plans to national coverage. The time seemed ripe for progressives. While the New Deal era provided a perfect opportunity for enacting national health insurance as progressive reformers sought, Franklin D. Roosevelt did not actually propose any health reform legislation, though there were commissions to investigate the matter and a call for a “right to adequate medical care” in his 1944 State of the Union address (Starr 2011: 39). He feared pushing the envelope too far, given the massive changes in the 1930s with Social Security, banking regulations, and the like. He also responded to interest group pressures – namely the AMA – and opposition from conservative legislators. In the end, though, it might not have been so much pressures opposing national health insurance as it was shifting

priorities caused by massive unemployment and economic insecurity during the Depression that required more proximate measures to help Americans back on their feet.

Despite the failures during the Roosevelt years, Harry Truman continued the national health reform effort throughout his presidency to no avail (Quadagno 2006). Political conditions were not favorable for a Truman national health care plan. Groups such as the AMA that favored private health insurance blocked all efforts for national health insurance. As noted above, national health care was not “the American way.” It was “socialized medicine,” to be avoided for fear of communism or some sort of German totalitarianism taking over the land. Nevertheless, small, fragmented gains were made during his presidency and on into the 1950s that helped build hospitals, paid for medical research, reimbursed states for the health care costs incurred by AFDC recipients (precursor to Medicaid), and fueled a proposal to aid seniors with hospital bills (foreshadowing Medicare) (2011: 41). Disability insurance also passed in 1956 with no real opposition. At the same time, there were small losses that hindered national health reform, such as the tax exclusion for employer contributions to health insurance passed under the Eisenhower administration (2011: 42).

National health reform efforts continued into the 1960s with a push from the National Council of Senior Citizens, an interest group created by the AFL-CIO (Quadagno 2004: 32). Older Americans demanded further protection in their retirement years in addition to Social Security, and they protested, marched, and lobbied their legislators for health care. Moreover, progressives wanted to ensure access to health care for everyone, including the poor and medically indigent. The response by conservative lawmakers was the Kerr-Mills Act in the early 1960s. This bill (modestly) increased health care access at the state level, and some states began offering prescription drug and nursing home benefits to low-income seniors under the Act, but it

was not enough. Interestingly, as Starr (2011: 45) notes, this bill, pushed by conservatives, mostly benefited liberal states. Again, as in the past, opponents to national health reform decried the progressive response to Kerr-Mills – hospital insurance for seniors – with the socialism bogeyman, but that did not deter public support for old-age health care assistance. After the death of Kennedy, pressure from Lyndon B. Johnson, and a new Democratic congressional majority after the huge Barry Goldwater defeat, the conservative bulwark and staunch opponent to progressive reform Ways and Means Committee Chairman Wilbur Mills conceded. He combined three separate policies, in an act of compromise between Southern Democrats and Republicans who generally opposed national health reform on one side and the liberal Democrats on the other, to form Medicare and Medicaid in 1965 (Grogan and Patashnik 2003; Quadagno 2006).

Because of eligibility restrictions, Medicaid does not meet everyone's needs who might be low-income or have a disability. In general, most non-disabled adults without children are not eligible. Many who are eligible do not participate for various reasons, which keeps many people uninsured who need care. Moreover, Medicare does not cover all health needs, thereby leaving room for private health insurance to complete one's coverage, if one can afford it. Then there were those many millions of Americans who still had no coverage through the government, family member, or an employer. Therefore, national health care remained on the national agenda.

In the early 1970s, there were competing policy proposals from the AMA and President Nixon that sought to expand health care through the private market. At the same time, Senator Ted Kennedy and the United Auto Workers union wanted to provide care through a single-payer system (Quadagno 2004: 34). Groups like the AMA and the National Federation of Independent Businesses vilified single payer systems as “socialized medicine,” much as they had in previous

decades. None of these proposals gained any traction. Neither did President Ford's national health care proposal. While the 1980s remained quiet except for improving Medicare benefits, the 1990s witnessed a resurgence of the national health care debate, which is important to discuss because it laid the groundwork for the success of Obama's plan in 2010.

President Bill Clinton in 1993 made health care a top priority calling for "America to fix a health care system that is badly broken. . . giving every American health security, health care that's always there, health care that can never be taken away" (Skocpol 1995:66). By that time, 37 million Americans were uninsured (Quadagno 2006). The conditions seemed to be ripe for serious comprehensive health care reform, as well as for its opposition. Twenty different health care reform proposals were on the table, including one from the AMA that guaranteed universal coverage. Initially, Clinton's plan received public support, but that support soon waned after campaigns against the plan began in late 1993.

According to Skocpol (1995), the Clinton plan failed essentially for three reasons. First, the Clinton administration did not explain the plan very well to the public and failed to mobilize stakeholders to support the bill. Second, the Democratic Party could not even come to a consensus on how the plan should work. Third, Republicans and anti-government conservatives succeeded in counter-mobilizing opposition that included right-wing talk radio (e.g. Rush Limbaugh), the Christian Coalition, the Health Insurance Association of America with their famous "Harry and Louise" commercials, think tanks, and the National Federation of Independent Business. Over the years, massive corporate lobbying by the health sector has helped to maintain the status quo and keep the federal government relatively inert in health care reform (Nack 2006). As a matter of fact, nearly 650 different interest groups spent more than \$100 million to influence health care reform in the early 1990s (Seelye 1994; West, Heith, and

Goodwin 1996), and advocacy groups based in Washington that were accustomed to insider lobbying dominated the reform environment (Hoffman 2003). In addition, over two-thousand news reports appeared on the issue of health care between September and November of 1993, but media rarely questioned the accuracy of the political ads that attacked the Clinton plan, with 59 percent of the television ads shown to be misleading or false. Outspending supporters of the Clinton plan over two to one, the Pharmaceutical Research and Manufacturers Association and the Health Insurance Association of America spent a combined \$34 million on political ads to attack the Clinton plan, while proponents of the plan, such as the Kaiser Foundation and the League of Women Voters, spent \$4.1 million (West, Heith, and Goodwin 1996). More money went into fighting it than supporting it, and there was more effort to discredit the whole idea than explaining it clearly to the American people.

Interest group opposition and media attacks took their toll. In all, public support for government-led health insurance declined significantly between 1993 and 1994 according to American National Election Study data.<sup>2</sup> In September of 1993, one poll showed that 67 percent of Americans favored the Clinton plan but by February 1994, support dropped to 44 percent. Then a second poll revealed a drop from 57 to 39 percent in favor of the plan, while another poll demonstrated a fall from 77 to 52 percent of respondents believing the Clinton plan would make them better off. Subsequent analysis did not find, though, that these changes in opinion were due to the widely publicized Harry and Louise ads and others like it (West, Heith and Goodwin 1996). Labor, a stalwart ally of the Democratic Party, also did not support the plan, due in part to

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<sup>2</sup> Source: American National Election Study 1948-2004 (Version of 10/2005). On a scale from 1 to 7, with 1 supporting private insurance and 7 supporting government insurance, in 1993 the mean response was 4.60 (n=345; SD=1.9) and in 1994 it was 3.98 (n=158; SD=2.00). There was a significant difference (p< .001) based on a two-sample t-test (t=9.67). Calculations my own.

the North Atlantic Free Trade Agreement Clinton supported that resulted in lost jobs for Americans.

Though Clinton's health care plan went nowhere, the basic idea undergirding it remained an essential component of future reform ideas, eventually leading to reform in 2010. The idea was "managed competition." Managed competition would entail introducing government subsidized health insurance to the private health insurance market in an attempt to make insurance more affordable to everyone. The subsidized plans would make the insurance market more competitive, in theory, thereby driving down prices overall. In 1994, The Heritage Foundation,<sup>3</sup> a conservative think tank, supported a similar proposal by Bob Dole, Republican senator from Kansas. His plan called for, among other provisions, "purchasing groups" or "non-employer associations" through which people could buy health insurance at a discounted rate without going through their employer, and subsidized health insurance through a tax deduction, to make health insurance more affordable. Under this plan, the government would compel people in some fashion to purchase health insurance to spread the total cost of health care across a broader public, much in the way people have to buy car insurance. The Heritage Foundation also faulted the Dole plan for its treatment of low-income families. They would have to buy an insurance plan with costly benefits they might not need or potentially see a higher effective tax rate. They did argue though that "[a]n assistance program for the working poor is necessary, but the cost will be high and there are many different ways to design and pay for such a program." In 2010, a solution to this problem arrived.

Rounding out the historical development of health policy in the U.S. to date is the Patient Protection and the Affordable Care Act of 2010 ("ACA"), called 'Obamacare' by conservative

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<sup>3</sup> M., Stuart. 1994. "Dole's Health Care Compromise: A Prudent Foundation for Reform." Retrieved March 11, 2016 (<http://www.heritage.org/research/reports/1994/07/does-health-care-compromise-a-prudent-foundation-for-reform>).

opponents. Unlike health care reform under Clinton in 1993, groups typically opposed to health care reform, such as the American Medical Association and the Health Insurance Association of America, did not mobilize opposition. The idea was to make health care available everyone, especially to the uninsured and underinsured, by mandating that citizens purchase health insurance either through their employer or through a state-based health insurance exchange, and by expanding Medicaid. The ACA ended a long-time practice of health insurance companies declining coverage to people due to pre-existing conditions. For instance, insurance companies could deny coverage to women for being pregnant before applying for insurance, or to college students who had a temporary gap in coverage while not enrolled in summer classes but became ill during that time. Under the ACA, children can remain on their parents' health insurance policy until they reach age 26. The ACA also requires insurance companies to spend more revenue on providing care than on administrative costs (i.e., profits), to cover preventative care, such as well-woman care and contraception, and to charge equal premiums to men and women. There are other improvements to American health care under the ACA worth noting, such as controlling costs and protecting patients, but I will focus on the component of the ACA that was most salient for the present discussion: Medicaid expansion.

Among other changes, the most profound for low-income persons and the working poor was that the ACA originally mandated that all states expand Medicaid eligibility to 138 percent of the federal poverty line, no matter a person's medical needs, age, or disability status. This provision of the law came at a critical time when the poverty rate increased and Americans were losing their health insurance due to job loss after the Great Recession of 2007. The first decade of the twenty-first century already saw a decline in health care access for many uninsured adults, when only half saw a doctor, a quarter saw a dentist, half had an unmet medical need, and a third

delayed care because of cost (Kenney, McMorrow, Zuckerman, and Goin 2013: 905). The rate of employer-provided insurance fell (63 to 58%), while the rate of uninsured increased (19 to 22%) (Holohan and Chen 2012: 5). Most individuals who were uninsured earned less than 200 percent of the federal poverty line. These individuals were far less likely to have employer-provided insurance and a greater likelihood of being uninsured than the average person. More children were insured in 2010 than in 2007, because of an increase in Medicaid enrollment. During the Recession, older white men disproportionately lost health insurance coverage from any source after becoming unemployed, mainly due to the high cost of insurance (Cawley, Moriya, and Simon 2015: 221). The increase in the unemployment rate during the Recession increased Medicaid enrollment for mothers and children and increased the likelihood of material hardship in comparison to years prior (Pilkauskas, Currie and Garfinkel 2012: 415). Even with increased spending on Medicaid during the recession as more individuals become eligible, some evidence suggests that there were negative physical and mental health impacts from the Great Recession, but the effect on health disparities is uncertain (Burgard and Kalousova 2015). More people either became eligible for Medicaid after 2007 or found themselves without health coverage and suffering because of it and would have benefited from an expanded Medicaid.

States received additional support from the federal government for a temporary expansion of Medicaid in 2009 under the American Recovery and Reinvestment Act to curtail the growing rate of the uninsured, but a more permanent solution was needed. The Medicaid expansion provision of the ACA requires the federal government to cover most of the cost of Medicaid expansion to states through 2020. States that do not expand their programs would have lost Medicaid funding, funds important to rural hospitals like Mercy Hospital in Independence,



KS,<sup>4</sup> and federally qualified community health centers. The idea was that Medicaid would cover those who cannot afford private health insurance through an employer or even on the discounted health insurance exchanges. However, the U.S. Supreme Court ruled the mandatory expansion unconstitutional by in 2012. Medicaid expansion then became voluntary.

It is instructive to note that Medicaid expansion was nothing new. Within a few years after the creation of Medicaid in 1965, some states voluntarily expanded their Medicaid programs (Olson 2010) in some cases to attempt to cover all uninsured. Throughout the 1980s, the federal government either provided the option to expand eligibility or made certain expansions mandatory. The idea of expansion was to increase access to health care for more low-income people, usually pregnant women and children. All states expanded their programs regardless of party in power, mainly because of the cost effectiveness of the expansions. In the case of the ACA, though, history took a different turn.

States led by Democratic governors expanded their state's Medicaid program, while most Republican-led states did not, initially. Many conservatives were against the ACA in its entirety from the beginning, and were especially troubled by the 'individual mandate' and Medicaid expansion, as they felt one was an attack on freedom and the other violated state's rights and the interstate commerce clause, among other reasons. Since its passing, Republicans in Congress have created 62 bills to repeal the ACA, with the last one in December of 2015 passing both houses of Congress only to be vetoed by the president.<sup>5</sup> Many Republican governors have

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<sup>4</sup> McLean, Jim. 2015. "Kansas Hospital Closure Sparks War of Words on Medicaid Expansion." *KHI News Service*. Retrieved March 15, 2016 (<http://www.khi.org/news/article/kansas-hospital-closure-sparks-war-of-words-on-medicaid-expansion>).

<sup>5</sup> Steinhauer, Jennifer. 2016. "House Votes to Send Bill to Repeal Health Law to Obama's Desk." *New York Times*, January 6. Retrieved March 15, 2016 ([http://www.nytimes.com/2016/01/07/us/politics/house-votes-to-send-bill-to-repeal-health-law-to-obamas-desk.html?\\_r=0](http://www.nytimes.com/2016/01/07/us/politics/house-votes-to-send-bill-to-repeal-health-law-to-obamas-desk.html?_r=0)).

ignored majorities in their own states who want Medicaid expanded, including Kansas.<sup>6</sup> At the same time, the Republican Governor's Association claimed in a 2011 letter<sup>7</sup> that the federal government largely ignored governors' "repeated efforts" to engage in debate on health care reform leading up to the passage of the ACA. In that same letter, Republican governors claimed that expanding Medicaid under the ACA would be detrimental states. It would cost too much money and it would overburden the already limited access to health care many Medicaid recipients experience. In response, they outlined seven "Principles" and thirty-one "Solutions" to reform Medicaid. The theme is "Flexible, Innovative and Accountable." According to Principle #1, "States are best able to make decisions about the design of their healthcare systems based on their respective needs, culture and the values of each state." In their view, Americans' health needs vary with geography. They also want to end what they believe to be a paternalistic system.

Principle #5 states

Medicaid recipients should have a stake in their personal health care, and the Medicaid program, by design, should make room for recipients to play a role in the decision-making process. Personal responsibility and consumer choice for Medicaid recipients must be standard components of a new Medicaid. Medicaid recipients, like the rest of Americans, should be given both the freedom to choose their health plans and the responsibility to contribute to their health care costs at a level that is appropriate.<sup>8</sup>

To summarize the letter, Republican governors want a block grant, no federal oversight, no guidelines for benefits structures, and to place as much responsibility on individual consumers as possible. Thus, expansion completely contradicts their position on Medicaid.

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<sup>6</sup> "Latest Kansas Hospital Association Poll Shows Strong Support For Medicaid Expansion." Retrieved March 5, 2016 (<http://kcur.org/post/latest-kansas-hospital-association-poll-shows-strong-support-medicaid-expansion#stream/0>).

<sup>7</sup> Republican Governors Public Policy Committee, Health Care Task Force, August 30, 2011. "A New Medicaid: A Flexible, Innovative and Accountable Future." Retrieved March 20, 2016 (<http://www.scribd.com/doc/63596104/RGPPC-Medicaid-Report#fullscreen>).

<sup>8</sup> Ibid.

Thus, 19 states – all Republican-led – have not expanded their Medicaid programs as of early 2016<sup>9</sup>. This partisan divide creates an obstacle to organized interest groups working to convince policymakers and publics that their states should expand Medicaid, but not too big of an obstacle. Lobbyists for private insurance succeeded in blocking expansion in many states, while public interest lobbies had a moderate impact on states that expanded Medicaid under the ACA, even though private interest lobbies outnumbered public groups four to one (Callaghan and Jacobs 2016: 311). Organizations like the National Association of Community Health Centers, National Health Care for the Homeless Council, Center on Budget and Policy Priorities, and the American Academy of Pediatrics, to name a few, provide resources for advocates of expansion. A variety of national advocacy groups like Families USA, Network (a progressive Catholic organization), and the National Hemophilia Foundation, among others, work to expand Medicaid in conjunction with efforts by state and local organizations. I turn now to advocacy organizations in health politics.

### **Advocacy Organizations in Medicaid Politics**

Advocacy organizations are voluntary associations independent of the political system that are either for-profit, advocating on the behalf of firms and industries for a fee, or non-profit, some of which represent a particular idea or cause that benefit broader publics beyond the members of the organization. They make public interest claims on behalf of certain constituents or ideas that, if successfully implemented in policy, would conflict with the social, cultural, political, or economic interests of other groups (Andrews and Edwards 2004: 481). According to Andrews and Edwards (2004), sociologists are becoming increasingly interested in advocacy

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<sup>9</sup> Kaiser Family Foundation. “Status of State Action on the Medicaid Expansion Decision.” Retrieved March 17, 2016 (<http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/>).

organizations, with particular concern for the civic engagement and social capital of national level organizations. They observe that knowledge of funding issues, the “free-rider problem,” and organizational structure has been advanced more so than interest group policy outcomes. They argue that the advocacy role of non-profit organizations, especially small, volunteer-run groups, needs more study. It is this latter type of group that I am interested in understanding.

The extent to which advocacy organizations actually influence policy and its outcomes, and *how*, is not especially clear (Andrews and Edwards 2004). Interest group politics is a site of contestation. Some groups, because of their economic and social capital, and because their interests tend to align with the ideological interests of policy elites, are well positioned to effect meaningful change (such as conservative groups opposing Medicaid expansion in Kansas), while others must struggle against the current to achieve even limited successes (such as those who favor expansion). Some research shows that political organizations have little impact on policy, except when they advance electoral aims of politicians (Burstein and Linton 2002: 398). Advocates have been able to influence policy and achieve modest gains for public assistance recipients at the state level (Butler and Seguino 2000; Simmons 2002). Advocacy organizations may seek practical solutions or provide a counter narrative to mainstream approaches to welfare (Harvey 2008: 162-3). They succeed by keeping policymakers engaged in a dialog, even if those policymakers are not inclined to do so or are disinterested, but the effectiveness of this dialog is predicated on 'discursive opportunity structures' (Ferree 2003; McCammon, Muse, Newman, and Terrell 2007) or frames that are culturally resonant (Kolker 2004: 822). Social movement success also depends on the willingness of policymakers to support desired changes, so we must understand the circumstances that foster their cooperation as well (McCammon, Campbell, Granberg, and Mowery 2001:50).

In light of their potential as political actors in shaping policy, and drawing on the social movements framing literature, Andrews and Edwards (2004) identify five dimensions of the policy process for advocacy organizations: agenda setting, access to decision making arenas, achieving favorable policies, monitoring and shaping implementation, and shifting the long-term priorities and resources of political institutions. As part of their agenda setting function, organized interest groups utilize “outsider strategies,” such as media use, to generate publicity and shape public opinion in terms of diagnostic frames, i.e. defining issues and assigning blame. Advocates access decision making through participating in advisory boards, legislative hearings, and meetings with state and federal officials, which could be ‘veto points’ or the opportunities to block policies. They achieve favorable policies if their interests align with those in power, or if they seek limited objectives. Advocates continue engaging the state after policy implementation to look for problems and find ways to make improvements, or simply to hold officials accountable. Finally, by keeping the state engaged, they may influence how officials make future policy. Shifting the priorities and resources of political institutions is akin to the distributive effects Best (2012) outlines. What Andrews and Edwards seek to understand through the framing concept are the processes by which advocacy organizations influence policy.

Conceptualizing advocacy organizations as social movement organizations is useful for studying Medicaid politics as contentious politics. Not necessarily in the sense that social movements scholars like Tilly, McAdam, Tarrow and others use the term ‘contentious politics’ (Tarrow 1996), but simply to emphasize the salience of competing claims in the face of a political structure that may or may not be conducive to influence from those who challenge dominant ideologies. Studying advocacy work can reveal tensions in how the state creates health policy in relation to advocacy organization activism. For instance, an advocacy group’s media

messages can highlight competing claims by stakeholders, how each side sees an issue and what the problem is and why. The access to policymaking an advocacy organization has could reveal the extent to which the state is open to public debate and alternative proposals, and what sort of access is even meaningful for shaping policy. How an advocacy organization's interests align with those of the state can indicate what political discourses, perspectives, and attitudes dominate, and what discursive barriers they encounter. Finally, what happens after implementation can not only show the influence of advocates on policymaking, but implementation can reveal future struggles and conflicts that could result in further activism or a change in advocacy strategy. Implementation can also reveal tensions between theory and practice, that is, policymakers purport that a policy can accomplish certain goals, but what happens in reality may be different. The reality of a policy is what actually affects consumers; therefore, advocates will use that reality in their struggle with the state to reshape policy. These are insights we could gain from analyzing advocacy organizations as social movement organizations. At the same time, it is important to consider the context in which these groups act.

Consumer advocates face strong currents against which they must swim to protect social program beneficiaries. At the heart of the conflict between advocates for expanded benefits and economic security through publicly funded programs and proponents of cuts to social services is capitalism. Capitalist ideology is the impetus behind the drive for ever-cheaper labor on the one hand and opposition to the state's influence on the economy on the other. From this perspective, the state should not compete with the market by giving individuals alternative ways to gain economic security and freedom. Because women and racial minorities, as well as persons with disabilities, disproportionately occupy less advantaged positions in American society, labor markets have not provided the same social mobility and financial stability experienced by many

white men without functional limitations. Exclusionary hiring practices, lack of appropriate accommodations, and institutional racial and gender discrimination make work a less viable means of independence for many Americans. Therefore, to ensure that people are included in society, the state instituted policies to give people options outside the market for survival. Cuts to these programs, though, mean that women and racial minorities in particular are negatively impacted. Hence, groups continue their struggle to ensure that everyone has a “fair shake,” while other groups continue to push for weaker social programs and more reliance on labor markets. This struggle is evident in how advocacy organizations have shaped Medicaid politics.

By placing Medicaid into a broader historical narrative, the role interest groups have played in the development of American health policy in general, and at least the emergence of Medicaid in particular, becomes apparent. Interestingly, historical accounts of the evolution of Medicaid itself, unlike Quadagno’s analysis of national health care, have centered on the role of politics defined narrowly as legislative politics at the national level (e.g., Engel 2006) with little mention of organized interest groups at the state level. For example, Smith and Moore’s book on Medicaid politics argues that developed in three stages, from a period of refining, to growth and to constraint, but the only factors that seemed to matter was ideological conflict and legislation (Smith and Moore 2010: viii). Grogan and Patashnik (2003), too, analyzed the evolution of Medicaid policy itself, the politicians and policies that informed it, and what progressives wanted from the program but without any mention of who these progressives were other than perhaps liberal legislators. Tanenbaum (1995) looked at the 1981 to 1990 period of Medicaid development only to note changes in the program nationally, arguing changes occurred according to policymaker views of beneficiary deservingness, a point Grogan (1997) explores, and what changes were most feasible (i.e., expanded eligibility to pregnant women and children

as they were the least costly group). Therefore, the extent to which organized interest groups have shaped the evolution of Medicaid is not clear without looking to specific states at certain points in time in relation to particular reforms.

A library search of the sociological literature on organized interest group influence on Medicaid yielded few relevant results, mostly tangential to my study. One study on the relationship between media attention to disease and advocacy group activity found that organized interest groups, especially large ones, increase media attention to disease, except in the case of AIDS (Armstrong, Carpenter, and Hojnacki 2006: 760). Evans and McGaha (1998: 619) found in their study of consumer advocacy in mental health policy in Missouri that individual consumers were unlikely to participate in an advocacy group because of barriers to access, such as lack of money, transportation, or knowledge of advocacy groups, their health problems, or not having a phone. However, some did make their voices heard by directly contacting their legislators. The point of their research, to me, was that advocacy organizations are important for ensuring consumers have a voice in the policymaking process, because individuals alone may not have the capacity to participate. Both of these studies show the importance of advocacy organizations for giving voice to stakeholders in health care, something I find important as a sociologist with an interest in social inequalities and social justice.

Broadening my search, I found that other studies tend to focus on whether advocates are successful in shaping policy, and there is some evidence to suggest they are. State-based advocacy organizations give a local voice, and local input has also been shown to matter for success of Medicaid managed care reforms in some states (Coughlin and Long 2004: v). For instance, consumer advocates have influenced nursing home reimbursement policy in New York and Minnesota to improve health care access, quality of care, and quality of life (Miller and



Rudder 2013). Public engagement, which often includes consumer advocates, has been essential to the success of dual eligible Medicaid-Medicare programs (Hodin 2013), such as pay-for-performance nursing home programs in Iowa, Minnesota, and Oklahoma that benefited from having “extensive stakeholder involvement,” including advocacy groups, patients, and providers, “throughout program implementation and development” (Miller, Doherty, and Nadash 2013: S156). Maskovsky (2000: 139) noted that an AIDS advocacy group successfully gained consumer protections after staging a protest against HealthChoices, the managed care plan that covers all Medicaid consumers in Philadelphia, PA. Their win was marginal. They wanted AIDS patients on Medicaid to be exempted from managed care, but that did not happen. His main takeaway was that the group’s activism offered a counter narrative to market-based solutions to health care for the poor, specifically consumer choice, but it was not necessarily meaningful for shaping policy. As Maskovsky stated, fear of bad press after the group occupied a welfare office and trashed it, among other things, resulted in the concessions they demanded. Sometimes advocates can make a difference, sometimes they do not, but it is not for a lack of trying.

Miller (2014) interviewed policymakers and stakeholders to understand Medicaid politics in Rhode Island, and he found that advocate voices were largely missing from the policy making process. Were they missing because they were organized out of the policy discourse? Willging, Semansky, and Waitzkin (2003) found that in New Mexico, advocates complained of not being included in the state’s Medicaid mental health managed care waiver renewal process. It was only after advocates created coalitions with other stakeholders locally and nationally and lobbied the state and federal government did they finally have a voice. Or did they just remain silent? Grogan and Gusmano (2007) explored why oppositional voices remain relatively silent in Medicaid policy reform. They found that participants in Medicaid advisory boards that claimed

privately to disagree with Medicaid managed care reforms were silent publicly, because they felt that their voices would not result in something feasible and worried that they might harm their relations with their non-profit service providers. The politics of Medicaid can be contentious given that different beneficiary groups and health care providers make competing claims and vie for limited resources (Kronebusch 1997). What these studies show is that advocates must have meaningful access to the policymaking process to have influence, and policymakers have to listen to them, unless they employ protest strategies to varying degrees. Even then, there is no guarantee of complete success. What these studies show is that advocates are likely not to bring about radical changes but only incremental adjustments to programs.

Not all scholars agree that the organized interest group framework is useful for understanding Medicaid politics (Davidson 1997). However, the argument has merit, and it is worth exploring further given the strong history of interest groups in welfare and health politics. In studies of welfare state change, sociologists have focused on political institutions, policy feedback effects, and welfare state structure (Pierson 1996: 152-3). Others look to political ideologies of parties in power, i.e., power resources theory (Korpi and Palme 1998), public opinion (Burstein 1998), public attitudes (Blekesaune and Quadagno 2003), and “social policy responsiveness,” or the influence of mass social policy preferences on spending and policy-making (Brooks and Manza 2006). These theories tend to explain welfare state expansion, but in an era of austerity, the “new politics” of welfare state retrenchment, characterized by a shift in goals from expansion to constraint of large social programs (Pierson 1996: 144; Korpi and Palme 2003), is more instructive for understanding contemporary welfare and Medicaid politics, especially since the Great Recession.

Pierson (1996) argues that retrenchment politics is distinct from the politics that guided welfare state expansion from the New Deal to the War on Poverty eras. Politics of expansion, he argues, was one of “political credit-claiming,” where progressive politicians could take credit for social improvements and defeating entrenched interests (1996: 144), whereas politics of retrenchment takes something tangible away from people and replaces it with uncertainty, and avoids blame for costs that tend to concentrate in specific groups (1996: 145). The concentrated interests engender social action and links to networks that keep these groups informed of how policies affect them. Because of a “negativity bias,” cuts to programs may be politically difficult (1996: 146), so proponents of austerity have to legitimate retrenchment policies. This is especially difficult in the face of large social programs that are now mainstays of the political environment. These programs have created interest groups that will try to protect them apart from those groups that helped bring the programs into existence, such as labor unions and social movement organizations (1996: 147). Inadvertently, the state influences the formation of groups, their political capacities, ideas, and demands (Skocpol 1989: 21) and organizes political activity (Quadagno 2004: 40). As a result, organized interest groups seek to influence public policy-making activities of elected or appointed public officials and represents status groups or some form of identity constituency (Lowery 2007). Indeed, many of these groups have been integral to health reform in the U.S. (Hoffman 2003; Moran 1999; Nack 2006; Orloff and Skocpol 1984; Quadagno 2006). An important component of retrenchment politics, then, is the policy feedback effect.

Public policy design influences attitudes and political behaviors that feed back into the political system and shape policy outcomes and future policymaking (Campbell 2011). Feedback effects can then influence the development, mobilization, and redirect the efforts of interest

groups (Gusmano, Schlesinger, and Thomas 2002: 733-4). Once established, large social programs are supported by entrenched interest groups that may try to inhibit efforts by the state or retrenchment advocates to cut back or constrain a particular social program, which makes these groups key actors in welfare state politics (Pierson 1996: 146-7). In other words, change in a social program, or the creation of a new policy, can engender action by stakeholders to form interest groups, which, in turn, reshape, or attempt to reshape, the program in a cycle of contentious reform politics. Retrenchment politics is best understood as a product of neoliberalism.

Since the 1980s, the American welfare state has shifted from government-based to market-based solutions for health and social care (Esping-Andersen 2000:5). After World War II, many advanced capitalist democracies extended various social rights to citizens through programs that gave them some relief from market forces (Esping-Andersen 1990:3). Economic growth during this period was increasingly more equitable, and capital was reaping a smaller share of total growth in the form of profits (Bambra 2009: 107). Globalization and greater competition in the global marketplace made it difficult for capitalists to earn a profit. In response, governments began shifting welfare benefits based on citizenship rights and redistribution to policies that emphasize growing the economy through markets and flexibility in production (i.e., offshoring and other domestic labor cutting mechanisms) (Harvey 2011: 75-76; Quadagno 2010). As a result, neoliberalism has expanded across advanced democracies (McNally 2011: 2). States facilitate flexibility in free trade, free markets, and protection of property (Harvey 2011: 2), increasingly couple labor power to markets, shift responsibilities of care to the private sector (Bambra 2009: 111), maintain austerity as a policy solution (Svallfors 2007: 2), and accentuate the state's historical role in the development of private markets (Block

2001: xxix). Thus, neoliberalization can be thought of as a state enterprise to intensify marketization and commodification of society (Brenner, Peck and Theodore 2010: 3) by both ‘liberating’ individual freedom of exchange and by creating and protecting free markets (Harvey 2011:2).

Though it has not taken the same form in all countries (Kus 2006; Brenner, Peck and Theodore 2010: 182; Plehwe 2009), neoliberalism has a consistent sensibility. The “hegemonic discourse of neoliberalism” (Harvey 2011: 3) posits that markets *should* provide for people’s needs, not the state; people *should* be more responsible for their own care, not public institutions; and social policy *should* provide pecuniary benefits and contribute to the growth imperative of capitalism, not invest in public wellbeing and institutions. Though the personal responsibility idea predates neoliberalism, neoliberalism integrates it into a larger discourse that deemphasizes social responsibility. As a theory of political economy, neoliberalism assumes that the social good is best achieved through market mechanisms, and that the virtue of markets and free exchange is taken for granted as conventional wisdom (Harvey 2011: 2-19). As a theory of knowledge, it structures how we think, know, and talk about the individual, the state, and the social, that is, everything should be thought of in terms of the market (Brown 2006: 694). It follows, then, that the American welfare state is a political institution that promotes markets and individual responsibility (Harvey 2011: 76) in the provision of care. This requires continued retrenchment and further privatization. As Myles and Quadagno (2000: 156) asked rhetorically, “who needs a welfare state when we have markets?” As such, if markets can (should) provide for all of our needs, then public institutions and politics are unnecessary and privatization of state functions, in particular health care, become imperative.

The neoliberal rationalization of the American welfare state is evidenced in the devolution of health and human services from the federal level to state and local government and (especially) to the private sector (Marwell 2004:267; Nelson 2005: 106), in other words, privatization. The idea is nothing new. Prior to the neoliberal era, the government used privatization to facilitate the expansion of benefits and eligibility, but now it functions to reduce 'welfare dependency,' cut costs, and grow the economy. It is about expanding markets in the public provision of care and make public programs more efficient by exposing them to market competition (Kim and Sakamoto 2010: 124). Setting the stage for policy today, the Private Sector Initiative of the Reagan administration gave an impetus for privatizing all sorts of public functions (Kamerman and Kahn 1989: 5).

Privatization is a product of fiscal federalism and delegated governance. Fiscal federalism is the idea of decentralized public finance. It "lays out a general normative framework for the assignment of functions to different levels of government and the appropriate fiscal instruments for carrying out these functions" (Oates 1999: 1121). Theoretically, public functions exist at a particular level of government based on its 'closeness' to the publics it serves and at the level that grants the most efficiency in provision, assuming imperfect information. AFDC, for instance, was located largely at the federal level, which allowed for the most equitable redistribution of income. However, "laboratory federalism" (1999: 1132) changed all that. Treating states as 'laboratories' for developing unique solutions has been one of the hallmarks of social policy reform. As Justice Brandeis said,

[...] It is one of the happy incidents of the federal system that a single courageous State may, if its citizens choose, serve as a laboratory; and try novel social and economic experiments without risk to the rest of the country (1999: 1132).

As such, the federal government grants more power to states to shape the American welfare state. For instance, in the 1990s, President Clinton encouraged states to explore innovative solutions to improve Medicaid, particularly through privatized managed care (Quadagno 2014:43). States had more power, and responsibility, to shape their health care systems, and they did so through the market. This process of delegating more responsibility to the states is called delegated governance.

Delegated governance of the welfare state has been a political strategy to maintain social protections without seeming to increase the size of government (Morgan and Campbell 2011: 8). Delegation involves creating public/private partnerships and such, but delegating the provision of care to lower levels of government and to non-state actors is more than just a public administration scheme. Contemporary delegation employs competitive market forces, pushes more decision making onto program participants (2011: 84), that is, consumer choice and personal responsibility, and purportedly increases efficiency and improves performance (2011: 121). Proponents of retrenchment will delegate responsibility to lower levels of government or to the private sector to avoid blame for policy failures (Pierson 1996: 177). The use of delegation in this way, as evidenced by the Reagan and Clinton initiatives, crosses political boundaries, which shows that it is becoming a taken-for-granted way of organizing social policy in the U.S.

In sum, neoliberalism has resulted in a more rationalized welfare state predicated on market principles. Policymakers see privatization as a way to increase the role of markets in the public provision of care to grow the economy and increase personal responsibility on the one hand, and reduce the role of the state in care on the other. In this context, it did not surprise me to learn that Medicaid has taken a similar path of neoliberalization. Kansas is no exception. In the next section, I lay out the case of KanCare, which was the comprehensive reform of Medicaid in

Kansas in 2013. It is the exemplar of managed care, neoliberalism, and broader changes in the welfare state.

## **KanCare**

The impetus for reform that brought about KanCare can be traced to 2006 when the Kansas Health Policy Authority began exploring ideas for reducing administrative cost, increasing coverage, and shifting Medicaid consumers to managed care plans (Kansas Department of Health and Environment 2009: 10). The Kansas Health Policy Authority was responsible for most of Medicaid and the Children's Health Insurance Plan. As the first step in its Medicaid Transformation Plan, the agency reviewed 14 major pieces of the Kansas Medicaid program to determine areas for "improvement, efficiencies and savings" (Kansas Department of Health and Environment 2015). The results published in a report in 2009 informed the changes in Medicaid to come.

Kansas spent roughly \$2.2 billion on Medicaid services in 2007<sup>10</sup>. About half of the cost went to medical care services, while the remainder went to long-term care and mental health. The cost increased modestly each year, but especially for persons with disabilities. The share of the total cost of Medicaid bore solely by the state actually declined from 39.4 percent in 2006 to 30.6 percent in 2010. This was likely due to federal stimulus spending after the 2007 recession, as the cost share began to increase after 2011 to 40.3 percent in 2013.<sup>11</sup>

The Kansas Health Policy Authority posited in its 2009 report that extending managed care to other Medicaid populations could save the state money. Kansas already had a managed care program called HealthWave, which covered primarily low-income families and children.

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<sup>10</sup> Medicaid Transformation Process— Executive Summary, p. 1.

<sup>11</sup> Medicaid Financial Management Report - Net Services. Retrieved January 29, 2016 (<https://www.medicaid.gov/medicaid-chip-program-information/by-topics/financing-and-reimbursement/expenditure-reports-mbes-cbes.html>).



Other beneficiaries were covered under HealthConnect, which was the traditional fee-for-service program. The overall cost per capita for HealthWave were lower than HealthConnect, but that had more to do with the fact that the HealthWave population was typically healthier than other Medicaid consumers. About 67 percent of Medicaid expenditures went to the aged and disabled population who were covered mainly under the fee-for-service program.

HealthWave had been the portion of Kansas Medicaid that provided coverage to pregnant women and children. Kansas introduced its first managed care program in 1999 to cover children but later incorporated it into HealthWave. The state contracted with FirstGuard Health Plan of Kansas – a subsidiary of Centene, to deliver the new managed care plan as an alternative to fee-for-service in 62 counties<sup>12</sup>. After identifying numerous performance problems with FirstGaurd, in 2007 the state contracted with two new MCOs to administer the non-mental health portion of the managed care program: Children’s Mercy Family Health Partners and UniCare. A third MCO, Cenpatico, began administering the mental health portion of HealthWave. Based in part on some of the cost and efficiency-related findings in the 2009 Kansas Health Policy Authority report, the incoming Brownback administration set out to further restructure Kansas Medicaid. In 2011, the state held a competitive bidding process and contracted out Medicaid administration and payment delivery to three for-profit MCOs: Amerigroup Kansas Inc., Sunflower State Health Plan Inc., and United Healthcare of the Midwest. The managed care waiver application was initially denied, because the state failed to include tribal groups in its planning of KanCare, but after meeting this shortcoming, the federal government approved the application on December 7, just in time for implementation on January 1, 2013, as planned.

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<sup>12</sup> Ranney, Dave. 2006. “FirstGuard Continues to Contest HealthWave Contracts.” *KHI News Services*. Retrieved January 29, 2016 (<http://www.khi.org/news/article/firstguard-continues-to-contest-healthwave/?print>).

KanCare enrolled all Medicaid groups in one of three managed care plans, the first state to do so. To help lower costs related to expensive institutional care, the state will enroll more consumers in the Home and Community Based Services waiver program so that they can receive care in their homes, but over 2,400 people are still on the waiting list for these services as of 2014. Another important change for Kansas Medicaid is the introduction of 'Health Homes' for serious mental illnesses and chronic health conditions. On July 1, 2014, KanCare began enrollment for people with mental illnesses, and those with chronic conditions will be enrolled later, as the necessary provider network was not yet complete. Health homes coordinate physical and behavioral health care with long-term care services for people with chronic conditions and connect those individuals to community and social supports<sup>13</sup>. It is a 'whole person' approach to providing comprehensive care. Better coordinating complex care arrangements is a way to be more efficient and cost effective while improving health and quality of care. People with diabetes, mental illness, or asthma qualify for health homes.

The idea of privatization was nothing new in Kansas. For example, in 1996 with the Department of Children and Families (then known as Kansas Department of Social and Rehabilitation Services) (Kansas Department of Health and Environment 2015) under Republican governor Bill Graves, Kansas has become the “first state in the nation' to implement 'full-service' privatization of its child support enforcement functions border-to-border.”<sup>14</sup> The earlier managed care programs in Kansas demonstrated a trend toward increased privatization, too. However, KanCare is a far more expansive, comprehensive system of health and social care

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<sup>13</sup> KanCare “What are Health Homes?” ([http://www.kancare.ks.gov/health\\_home/consumers\\_what\\_is\\_hh.htm](http://www.kancare.ks.gov/health_home/consumers_what_is_hh.htm)).

<sup>14</sup> Ranney, Dave and Mike Shields. 2014. “Privatization initiative offers window on Kansas government: Child support enforcement story blends politics, policy and procurement.” *KHI News Service*. Retrieved June 1, 2015 ([www.khi.org/news/article/privatization-initiative-offers-window-kansas-gove/#sthash.R2ksmp7D.dpuf](http://www.khi.org/news/article/privatization-initiative-offers-window-kansas-gove/#sthash.R2ksmp7D.dpuf)).

that affects almost 400,000 Kansans, not including the health care providers that serve them. I turn now to the broader policy changes in which KanCare emerged to place KanCare in context.

### **KanCare in Context**

Social programs are becoming more market oriented and placing more emphasis on the value of work and self-sufficiency. In Kansas, TANF eligibility is set at 32 percent of the federal poverty line, one of the lowest in the country. Since 2005, Kansas has enacted policies to reduce caseloads<sup>15</sup> with enrollment at its highest around 2006 and dropping from about 44,500 to 15,000 since then.<sup>16</sup> Some of the largest decreases in caseloads came after TANF and Medicaid applications were separated into two forms. Recipients were required to make 20 work contacts per week in 2011 and to register with the state's public workforce system and complete a work skills assessment in 2013. The state reduced the time limit to receive cash assistance from 60 months to 48 months in 2012. It offered the option of a \$1,000 diversion payment. If an applicant accepts it, they become ineligible for cash assistance for 12 months and are limited to a 42-month lifetime assistance limit, but very few applicants took that option. In 2013, Kansas began requiring drug testing of TANF participants if there is suspicion of drug use or abuse. "The TANF suspicion-based drug testing program will allow parents to care for their children in their own home and enhance the opportunity to become self-sufficient families" (KDCF 2015). Interestingly, studies show that rates of drug use disorders are only slightly higher among TANF recipients than among the general population, and that, in fact, drug use has been declining since

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<sup>15</sup> Kansas Action for Children, TANF Report. Retrieved September 15, 2015 (<http://kac.org/wp-content/uploads/2014/11/TANF-Report.pdf>).

<sup>16</sup> Department of Children and Families. Retrieved September 15, 2015 ([http://www.dcf.ks.gov/services/ees/Documents/CURRENT\\_PAR\\_SF2015\\_Access.pdf](http://www.dcf.ks.gov/services/ees/Documents/CURRENT_PAR_SF2015_Access.pdf)).

the early 1990's (Schoppelrey, Martinez, and Jang 2003: 144-15). From July to September 2014, four TANF beneficiaries lost their eligibility due to the drug testing policy.<sup>17</sup>

In relation to the work requirement of TANF, Kansas created programs to encourage the poor to find work. Through the Work Opportunity Tax Credit, Kansas businesses receive a federal tax credit when they hire individuals from certain targeted groups. This federal program stopped accepting new applications for the credit in 2015, but it was one way Kansans on public assistance could gain employment in the private sector. However, hiring is at the discretion of private employers according to their needs and the qualifications of the individual candidate. In addition, candidates must reveal to employers their status as a recipient of public aid, which could be stigmatizing and an invasion of privacy. Similarly, the KANSASWORKS Employer Partner Incentive connects persons with disabilities to employers. Employers receive a monetary benefit per each person with disabilities hired after signing on to the program (Kansas Department of Commerce 2015a).

Workfare programs have not been effective at reducing poverty rates, though welfare retrenchment has cut rolls (Weigt 2010: 566; Lavee and Offer 2012: 375; Morgen, Acker, and Weigt 2010). People still have trouble paying for rent, food, utilities, and needed medical care (Hennessy 2005), because the poor encounter many individual and social barriers in labor markets (Dworsky and Courtney 2007; Haynie and Gorman 1999; Kim 2009; Stromwall 2002; Sullivan and Larrison 2003). In June 2015, for instance, 900,000 Kansans lacked post-secondary education credentials that could afford them better job opportunities, and there were 32,000 available jobs, many of which require post-secondary credentials (Kansas Department of

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<sup>17</sup> Dept. of Children and Families. "Caseload Reduction Report." Retrieved September 15, 2015 (<http://www.dcf.ks.gov/services/ees/Documents/Reports/Kansas%20FFY%202015%20TANF%20All%20Families%20Caseload%20Reduction%20Report.pdf>).

Commerce 2015b). Moreover, the minimum wage in Kansas as of 2014 was \$7.25 per hour, which can bring home an annual salary of about \$15,000, if one worked 40 hours a week 52 weeks in a year, which is just below the federal poverty line for a family of two (\$15,930 in 2015). Nationally, about 70 percent of people working jobs at or below minimum wage are part-time, which means one might have to work more than one job to make ends meet. People are taking more responsibility for their welfare by working, though it may not help them to escape poverty or relieve the need for assistance with health care or food. Yet even food assistance may be helping people less.

Along with workfare were cuts to nutrition assistance expenditures to encourage more personal responsibility. After deciding against renewing a federal waiver that allowed unemployed and childless citizens to receive help buying food through the Supplemental Nutrition Assistance Program, or SNAP, some 20,000 Kansans lost their “food stamp” benefits. Hailed as “help, the opposite of cruel,” ending their program participation would incentivize people to find work.<sup>18</sup> A state official said that “[w]e believe the jobs are there and these people can work. And if you can work, you should work.” However, many individuals will likely seek out already strapped private community resources for assistance, because they will not be able to find work or what work they do find will be insufficient to afford an adequately nutritious diet. Federal rules already prohibit unemployed, childless adults from receiving SNAP benefits for more than three months in a three-year period, but many states including Kansas had been providing augmented benefits to this group under a waiver. In 2013, the average monthly SNAP benefit was \$124.87, while the U.S. Department of Agriculture “thrifty food plan,” which is their

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<sup>18</sup> Shields, Mike. 2013. “Food stamp rules to change for about 20,000 Kansans: DCF officials won't seek renewal of federal waiver; requirements stiffened.” *KHI news Service*.. Retrieved June 1, 2015 (<http://www.khi.org/news/article/food-stamp-rules-change-about-20000-kansans/>).

recommendation for a “healthful diet on a minimal-cost budget,” costs a family of four with two children over age 11 about \$647.50 per month<sup>19</sup>.

Overall, from 2009 to 2010, over a quarter of the U.S. population experienced a period of poverty that lasted for at least two months, and about five percent lived in poverty for the entire two-year period (DeNavas-Walt, Proctor, and Smith 2012: 4). By 2011, the official poverty rate was 15 percent, the same as it was in the early to mid-1990s, and varied widely between Whites (10%), Blacks (27%), Hispanics (25%), and Asians (12%) (2012: 13-15). In the last 40 years, the proportion of the poverty population living in “deep poverty” has increased from a low of 29.9 percent in 1975 to 43.8 percent in 2013 (U.S. Department of Health and Human Services 2015). Just telling people to be more responsible and get a job does not seem to match the realities many people face (Butler and Seguin 2000: 5), given the inequities for women and racial minorities in labor markets (Haney 2013; McCall 2001). In effect, those who need help the most are less likely to receive it under TANF, and those that do manage to find their way above the poverty threshold are not much better off and find themselves struggling. One way policymakers tried to help the poor was by expanding Medicaid under the health care reform of 2010, but in Kansas, that has yet to happen.

In Kansas, groups like the Big Tent Coalition and the Disability Rights Center, Kansas Action for Children, the Kansas Health Consumer Coalition, and especially the Kansas Hospital Association have been fighting for Medicaid expansion. They have faced an uphill battle with a governor and many legislators stalwartly opposed to expansion, citing reasons from exploding costs and fears that the federal government will not pay its promised share of the cost of

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<sup>19</sup> U.S. Department of Agriculture. “Cost of Food.” Retrieved September 16, 2015. (<http://www.cnpp.usda.gov/sites/default/files/CostofFoodJul2015.pdf>).

expansion<sup>20</sup> to the moral reprehensibility of expanding Medicaid while people are still on waiting lists for home and community based services.<sup>21</sup> In a 2014 interview with the Heritage Foundation, the governor of Kansas said that he believes the federal government will not be able to pay its share of the cost of expansion as promised due to the rising national debt, even though the ACA requires the federal government pay for most of the expansion. Making a distinction between the deserving and undeserving poor, the governor explained further that instead of relying on Medicaid expansion and other government programs that help relieve poverty, the “able-bodied” poor should get a job and find health coverage that way, despite the fact that the majority of people living in poverty already have jobs. Instead, the state should focus on helping the “needy” poor get off the home and community based services waiting list. The governor also explained that the costs of broadening eligibility might divert funds from expanding in-home care services to those on that waiting list, which has over 2,000 people. In other words, a concern over potential costs, a fear of the Federal government’s purported fiscal imprudence, and the cultural discourse of deservingness undergird the governor's decision to not expand Medicaid.

The Kansas governor is not alone in his opposition to Medicaid expansion. For example, voices of Medicaid expansion in the legislature, three moderate Republicans who were possible allies of expansion advocates, no longer have seats on the House Health and Human Services Committee after the House Speaker moved them to other committees in 2015.<sup>22</sup> Americans for Prosperity, a David and Charles Koch funded advocacy organization, also joined Kansas

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<sup>20</sup> KHI News Service. 2015. “Republican Talking Points Memo on Medicaid Expansion.” Retrieved March 15, 2016 ([http://www.khi.org/assets/uploads/news/13929/republican\\_memo.pdf](http://www.khi.org/assets/uploads/news/13929/republican_memo.pdf)).

<sup>21</sup> Marso, Andy. 2016. “Disability Group: Stop Citing Waiting Lists to Oppose Medicaid Expansion.” *KHI News Service*. Retrieved March 15, 2016 (<http://www.khi.org/news/article/disability-group-stop-citing-waiting-lists-to-oppose-medicaid-expansion>).

<sup>22</sup> Mclean, Jim, and Andy Marso. 2015. “Medicaid Expansion Supporters Booted from Health Committee.” *KHI News Service*. Retrieved March 15, 2016 (<http://www.khi.org/news/article/house-health-committee-overhauled>).

conservatives in their fight against Medicaid expansion.<sup>23</sup> Kansas appears to be one state where advocates will struggle and may never gain an inch, but the fact that they are struggling indicates that some publics have a strong interest in expanding social assistance to groups some policymakers might consider ‘undeserving.’ Overall, the ACA and Medicaid expansion are ongoing issues that serve as points of contention in health politics, with Republican presidential candidates vowing to overturn the ACA the day they take office, if elected, while Democratic candidates pledge to move it forward or propose to expand Medicare for all.

## **Conclusion**

The purpose of this chapter was to provide the historical and theoretical context for analyzing KanCare. The history of the American welfare state and health care reform has been one of conflict between organized interest groups and state actors. The political and economic environment has changed over time, as have the politics of the welfare state. Retrenchment politics drives social policy change now rather than expansion of benefits. It is in this context that emergent conservative views about the need for marketization and individual responsibility have taken hold in Medicaid, with consumer-oriented managed care as the dominant idea in Medicaid politics. Consumer advocacy organizations can expect to work to mitigate losses for program beneficiaries. What is uncertain is how well these groups can succeed, though there is evidence that they can make a positive difference for consumers given the right conditions. It is important, then, to understand what political and structural conditions advocates face, along with what they do to bring voices of disadvantaged groups to the policymaking process. Connecting the conflict between consumer advocates and their constituents and proponents of neoliberal

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<sup>23</sup> McLean, Jim. 2015. “Group that Opposes Medicaid Expansion in Kansas also Fighting Florida Bill.” *KHI News Service*. Retrieved March 20, 2016 (<http://www.khi.org/news/article/group-that-opposes-medicaid-expansion-in-kansas-also-fighting-florida-bill>; <https://americansforprosperity.org/afp-informs-voters-of-lawmakers-medicaid-positions/>).



reforms to larger social and historical trends brings a sociological perspective to Medicaid in the health policy literature. A sociological perspective helps us understand why the idea of Medicaid managed care emerged, why the idea persists, but, more importantly, how groups might challenge the neoliberal discourse undergirding these sorts of reforms to mitigate the negative impacts of changes to Medicaid for beneficiaries. In light of the political conflict, we need to know what consumers need and how the implementation of neoliberal reform affects them and their health care providers. This is especially important given the mixed results of consumer-oriented managed care reforms to improve Medicaid. Hence, this is the impetus behind studying KanCare. Kansas implemented the most comprehensive market reforms in Medicaid to date in an effort to reduce costs, improve health outcomes, and improve the quality of care. Given the history of competing stakeholder voices on the one hand and the mixed results of market-based solutions in Medicaid on the other, it is important to understand how KanCare emerged, how advocates played a role in its development, and what impacts it has on consumers and their health care. In the next chapter, I discuss the method of the study.

## CHAPTER 2

### Method

#### **Introduction**

This study uses qualitative research strategies, specifically interviews, document analysis, and participant observation, to explore the evolution of health policy in Kansas. I use these strategies to address the following three questions. (1) What is KanCare and how was it enacted despite the contentious politics around it? (2) How has KanCare affected consumers, or the beneficiaries of Medicaid? (3) How has KanCare affected the provision of health care in Kansas for KanCare consumers? The first question gives insights into what KanCare is, who was involved in its development – both state and non-state actors, the processes by which KanCare evolved, and what political conflicts existed and how they were resolved. Answering the second question identifies consumers' needs, wants, and experiences, what they think about KanCare, if they think their situations improved under the new system. Addressing the third question reveals the realities of KanCare implementation for those who provide care to consumers. In this chapter, I explain my research strategy, how I recruited research participants for interviews, who participants are, how I collected documents for analysis, what my observations entailed, and how I collected and analyzed data.

#### **Research Strategy**

Inspired by Morgen, Acker, and Weigt (2010), who examined the impact of welfare reform in Oregon from the perspectives of welfare recipients, case workers, and policymakers, I wanted to understand Medicaid reform in Kansas from the diverse points of view of consumers, providers, consumer advocates, and policymakers. Other studies that assess the impacts of social

policy on constituents (Lavee and Offer 2012; Morgen, Acker, and Weigt 2010; Waitzkin, Yager, and Santos 2012) suggest that these diverse perspectives would provide a ‘thick description’ of the reform process, the experiences of affected groups, and implications of the new system. As this is an exploratory study, I wanted to paint as broad a picture as possible so that I could gain insights into the different facets of reform: how it impacted consumers, how policymakers actually created health policy, what implementation of reform entailed for providers. Sometimes, the only way to collect data about certain problems “is some combination of observing what is going on, talking in rather loose, sharing, fashion with the people in the situation, and reading some form of document that they have” (Glaser 1965: 436). This is what I set out to do.

This case study of KanCare is comprised of participant observation, in-depth interviews with policymakers, KanCare consumers, and health care providers, and a content analysis of documents that give voice to state officials and a health care consumer advocacy organization. A qualitative approach permits an analysis of the relationships between personal troubles and public policies created to address those troubles from the perspectives of those who experience them (Denzin 2001: 2) and people’s meanings and understandings of their lives (Lau and Schlesinger 2005: 79; Warren and Karner 2010:6). Interviews gave a sense of what people thought about KanCare, how consumers felt changes in the program affected them, what meanings consumers attached to being a KanCare beneficiary, and what implications providers thought the new policy had for the practice of health and social care. It was possible to infer from consumers’ and providers’ experiences how KanCare worked in practice. A comparison could then be made between what occurs in reality, according to consumers and providers, as well as advocates, to how policymakers frame KanCare, that is, how it is *supposed* to work. Finally,

interviews with policymakers would complement data from state officials and advocates through document analysis, such as nuances of KanCare policy, what it is designed to do, problems with the design, and successes. In this case, the relationship may be one of tension between how policy is supposed to work and how it actually works in practice. The only way to know the latter is to talk to consumers and providers. Therefore, a qualitative approach helps to make necessary connections between lived experiences and how those experiences change, or remain the same, within a policy context. At the same time, qualitative strategies allow me to triangulate the data for more comprehensive and nuanced analyses as themes, sometimes unexpectedly, emerge.

When I began my research in 2012, KanCare was still in the process of development. I wanted to watch the reform unfold through implementation and its continued evolution after implementation. As such, I needed to have flexibility in my research design. I was in the process of learning about Medicaid in Kansas, learning who the key actors were, what the potential problems could be, and in fact, it was not even completely certain that the program would begin on time in January 2013. So much was uncertain for me, that I needed to be able to adjust my priorities. That is, would I be asking the right questions? Would I miss an important issue to talk about? Would there be someone new I should talk to for insights that I might miss otherwise? Qualitative strategies permit flexibility in the research process, because knowledge cannot be taken for granted *a priori* and must flow from a process that changes as the research proceeds (Rock 2001: 30). I learned something new each time I attended a public event, so the participant observation forced me to rethink how I would approach my consumer and provider interviews. I suspected themes would emerge in early interviews that I did not expect, which was the case. I had to be able to change the wording of questions or the order of questions depending on how

previous interviews went, and add new questions or change them depending on emergent themes. Qualitative methods, thus, was the appropriate choice for this study.

To understand how KanCare affected consumers after its implementation in 2013, I had to learn what it meant to be a Medicaid consumer in Kansas. The best way to do this was to talk to consumers to find out what their health needs are, what challenges they face, how they face them, and what their thoughts were on KanCare. I also wanted to know what impact KanCare had on health care providers, and so again, as with consumers, I felt the best way to know was to talk to them. Any impacts on the provision of care could have implications for consumers, so talking to this group was important. Understanding the politics of KanCare was a bit more complicated. Interviewing policymakers was a start, but I needed more.

I knew from the literature review that interest group politics and advocacy groups were important for social policy, but I did not understand what that meant in practice for Medicaid. I also learned through my early reading about KanCare, informational interviews, and participation in public events about KanCare that advocacy organizations played a role in Kansas health politics, but I did not understand how. Other studies rely on interviews with advocates, but I did not think interviews would reveal much beyond what public statements by advocacy groups would reveal. Instead, I felt that an analysis of documents that reflected what advocates were saying in relation to the official narrative from the state would better demonstrate a dialog between officials and advocates, which is what I wanted to capture. Documents are more than resources for researchers and containers of content. They can be thought of as “active agents in episodes of interaction” (Prior 2013: 419). The documents that interested me were transcripts of legislative hearings where state officials and consumer advocates testified, letters written by state officials, and media messages by advocates. These sorts of texts are written forms of what actual

people said in relation to others and in a context. Along with voices of actors, other types of documents, such as policy documentation, contain content that may reflect ideological positions and assumptions of those in power about health, health care, and consumers. These documents themselves also have power, in a sense, as they shape the discourse on Medicaid. Documents can “instigate and direct” (Prior 2013: 428). In sum, from my early research and participant observations, I developed a case study of KanCare using qualitative strategies that would allow me to explore KanCare in-depth, generate a thick description of the reform, and gain insights into KanCare, its politics and outcomes for different groups.

### **Interview Recruitment and Participant Demographics**

I used a combination of convenience and snowball sampling to recruit consumers, providers, and policymakers in 2013 and 2014. To reach consumers, I contacted consumer advocacy organizations for assistance<sup>24</sup>. Two of them placed an ad for my study in their newsletters, one online and one in print. I reached out by email to a consumer who had provided testimony on his own behalf at a KanCare Legislative Oversight Committee hearing. His name and contact information was a matter of public record on the Kansas legislature website in the form of a document he submitted to be on the record for the meeting. I asked providers I interviewed permission to place flyers for my study in their offices to help recruit consumers. Friends and family also helped to spread the word about my study to consumers they might know or to people who know a KanCare consumer.

To reach providers, I emailed a health care provider advocacy organization, Kansas Advocates for the Medically Underserved, who provided me a list of fourteen health care providers with the email addresses of their directors. They were clinics and hospitals in eastern

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<sup>24</sup> I emailed Kansas Health Consumer Coalition, Kansas Advocates for Better Care, and Kansas Action for Children.

Kansas that accept Medicaid and some that are safety net clinics that do not accept Medicaid. Some were community health centers. After excluding hospitals and the providers that did not accept Medicaid, I had a list of five providers and contacted them all by email. I excluded hospitals, because I was more interested in primary and preventative out-patient care settings, not emergency or in-patient care facilities. Through an informant, I emailed a non-profit organization that provides in-home care and asked for an interview, and through another informant, I requested an interview with the owner of a private physical therapy clinic that sees Medicaid patients.

I emailed all 11 senators and representatives on the Bethel KanCare Legislative Oversight Committee. I also emailed legislators representing the following counties in Eastern Kansas: Shawnee, Johnson, Douglas, Jefferson, Leavenworth, and Wyandotte. Those were the counties from where I was most likely to interview providers and consumers. I was advised by several legislators that the best way to reach them was by email. As one legislator told me (paraphrasing), “they are elected officials, so it is their job to respond.” Finally, I posted an ad on the Facebook site for Medicaid expansion advocates in Kansas and an ad on Twitter using the ‘hashtags’ #KanCare, #Medicaid, and #Kansas. The message was a shortened version of my flyer.

In response to my recruitment efforts, I received phone calls from five consumers and an email from one other. One of the phone calls was on behalf of two consumers together. Two consumers responded to my flyer, while others contacted me after learning of my study through a friend, family, or informant. I received emails from all the providers I contacted. One provider provided me the name of another provider to contact during our interview. This person also returned my email. I received an email from Cross-Lines, a non-profit organization in Kansas

City, KS, which serves low income individuals and families, advising they would like to speak to me about the study after receiving a referral from an informant. I received responses from four legislators. A representative and a senator agreed to an interview, a representative sent me a written statement by email that addressed most of my questions, and another representative asked me to call them at home, but, after trying to call, was unable reach the individual for an interview. I also met one representative through an informant. So I was able to secure three interviews and a written statement from legislators. I received a response from my Twitter post from someone at the Kansas Department of Health and Environment who then referred me to a public information officer in the governor's office that worked on KanCare. I emailed the individual who then agreed to a phone interview. After interviews with consumers and providers, I asked participants to provide my contact information to others they think might be interested in participating in my study.

I asked research participants where they would like to meet for an interview. I met three consumers at a public space – two at a library and one at a university student union. I met three at their apartment buildings in a common area. I interviewed one over the phone at his request, because of his health issues at the time. I interviewed all providers but two at their offices. I met one at a coffee shop, and I interviewed another over the phone at her request. One of the providers wanted to include one other person in the interview. When I arrived to that interview, expecting two participants, another two arrived for a total of four. I interviewed the legislators in different places: one in her office in Topeka, one at her church, and another at a university student union. The public information officer agreed to a phone call.

I interviewed six KanCare consumers and one family caregiver of a consumer, ten health care providers, three Kansas state policymakers, and a state policy analyst for a total of 21



interviews. An additional legislator did not grant me an interview but instead provided a written statement by email in response to my questions, which gave a total of 22 research participants. I did not include the interview with the individual from Cross-lines, as the data did not match well with other providers. I used the interview as information about poverty in Kansas. I will describe each interview sample below. In Table 1, I provide demographics for consumers and providers, and in Table 2, I provide demographics of policymakers. For anonymity, I asked providers for age ranges only, as the health care provider community around KanCare is small, and I limited descriptors of policymakers to political identity and gender, as reflected in their pseudonyms. Consumers were from eastern Kansas. Most were female and persons with disabilities, while one man had a serious illness. All were adults from their late 30's to early 60's. All participants had at least a bachelor's degree and two had graduate degrees. All have had jobs at some point in their adult lives but are currently unemployed and either receive income through Social Security or a family member. I interviewed each person individually, except for two whom I interviewed together because they were friends and lived in the same building.

The health care providers I interviewed were directors of community health clinics, administrative staff from a non-profit organization that provides in-home care, the director of a grassroots organization that assists persons with disabilities with their in-home care attendants, a physical therapist, and a community dental health clinic director. All were women but one. All had been in the health or social care field for over five years, and in some cases, for well over 20 years. They all had experiences with Medicaid prior to 2013, most even prior to when managed care first enacted in Kansas. Providers were mostly from Eastern Kansas, while one was from a county in southeast Kansas.

**Table 1. Demographics of Respondents: Consumers and Provider**

Respondents	Pseudonym	Age	Race	Occupation
Consumers				
	Agnes	62	White	None
	Robert	63	White	None
	Michael	53	White	Writer
	Brian	37	White	Student
	Sarah	41	White	Self-employed
	Denise	48	Black	None
	Gary	50	White	Teacher
Providers				
	Nancy	60s	White	Physical therapy, owner
	Rachael	60s	White	Community health, Director
	Lauren	40s	White	Community health, Director
	Eric	40s	White	Community health, Director
	Brenda	40s	White	In home care, Nurse
	Patty	40s	White	In home care, Nurse
	Cindy	30s	White	In-home care, billing
	Heather	20s	White	In-home care, billing
	Kristen	40s	White	In home care for disabilities, Director
	Gayle	50s	White	Community oral health, Director

**Table 2. Demographics of Respondents: Policymakers**

Pseudonym	Political Identity
Michelle	Moderate Republican
Holly	Moderate Democrat
Nora	Liberal Democrat
Scott	Conservative Republican
Billy	n/a

The four legislators that participated in the research covered the political spectrum in mainstream Kansas politics: one liberal Democratic representative, two moderates - one Democratic senator and one Republican representative, and a conservative Republican representative in the Kansas Legislature (the liberal and moderates described themselves as such, the conservative label I gleaned from the written statement and public record). The one moderate Republican was introduced to me by an informant. The other three were a product of chance.

That is, I did not purposely select individuals from across the political spectrum. This was merely a convenient unintended outcome. Three of the legislators were women, one was male. The public information official was male.

### **Participant Observation**

I wanted to learn as much about KanCare as I could, so I visited the official KanCare website ([www.kancare.ks.gov](http://www.kancare.ks.gov)) and started reading. I also talked with a former director of Medicaid, the director of a consumer advocacy organization, the owner of a physical therapy clinic, a state legislator, and a scholar who studies persons with disabilities who receive Medicaid benefits to gain insights on Medicaid and the proposed reform. In this process, I learned that the state of Kansas was going to hold public meetings about KanCare for consumers and providers. Therefore, I attended four of these events in late 2012 and early 2013. I attended a fifth public event about KanCare that was organized by community members, and not the state. This was the beginning of my empirical research, which provided a foundation for the interviews and document analysis.

As part of their public outreach required by the federal government, state health agencies held a series of public meetings across the state for consumers and providers. Meetings were held in 12 cities in late July, September, and November 2012 for a total of 36 meetings prior to implementation, and then a series of 30 more meetings in cities across the state during the first 90 days of 2013 for a total of 65 consumer events overall with 3,700 beneficiaries in total attendance<sup>25</sup>. Video recordings of the meetings were posted to the KanCare website, and there were teleconferences scheduled for those who could not attend, as well. Attending these

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<sup>25</sup> Presentation by Effie Swanson, Kansas Department of Health and Environment, Division of Health Care Finance to the American Academy of Pediatrics Kansas Chapter on April 19, 2013. Retrieved September 10, 2015 ([www.kancare.ks.gov](http://www.kancare.ks.gov)).

meetings was a way for me to immerse myself in the KanCare world. I wanted to see who consumers were, hear what state officials had to say about KanCare, and hear how individuals responded to the issues raised. I took field notes on each occasion and transcribed them later.

Two of the events I attended were formal informational presentations by state officials for consumers – one in Olathe, KS, in September 2012 and one in Lawrence, KS, in November 2012. The presentations were informative, with a question and answer part. There were perhaps as many as 150 people or more at the first meeting I attended, and not quite that many at the second one (by my own estimates). The audience was mostly white, but there were many non-white individuals, and a few with visible physical disabilities or illnesses (e.g., sitting in a wheelchair, or using a breathing machine). There were older couples and individuals, young families with children, and the occasional woman with a small child. I saw members of the Kansas City area print media present at each meeting, as well. Consumers at the first meeting had the option of a separate session in either Spanish or Russian. I felt like I was attending a seminar.

Each of the two-hour consumer meetings in Olathe and Lawrence were divided up into two parts. The first hour was a formal presentation about KanCare by Kansas Medicaid officials, and in the case of the second meeting MCO representatives, complete with PowerPoint slides explaining the changes and new services. The second hour was a question and answer session during which attendees could write down a question on an index card, hand it in, and have it answered by a state or MCO expert on that particular topic. Over half of the people in the audience left after the formal presentation during the first meeting I attended, leaving fewer people for the question and answer session. Many of the questions asked by consumers were questions that could be answered just by reading the KanCare website (which I did before

attending the events), or were issues that were addressed earlier in the presentation. Questions tended to be about an individual's specific problem, not about KanCare in general or about its goals. The most common question I heard at both events I attended was 'what will change for me?' If the experts could not answer their questions at that time, they asked for the person's contact information and offered to follow up with them at a later time, or asked them to speak after the meeting was over. One of the only questions I heard that was not about an individual personal problem was at the Olathe forum. A person asked how the MCOs will profit while lowering costs and not cutting benefits or reimbursement rates. The answer given by a state official was "the efficiency of the market." In all, my sense of these public events was one of feeling like I was being instructed, given information in a paternalistic manner that I could not really engage with in any meaningful way. It was not a moment for public discourse, it seemed to me. It was unidirectional. Nevertheless, the meeting began suggesting to me the kinds of questions to pose to consumers in interviews about their needs and experiences.

The second event in Lawrence was interesting. At this event, each MCO had a kiosk set up outside the auditorium at Lawrence Memorial Hospital where attendees could pick up assorted KanCare-related paraphernalia, including brochures, pens, a giant daily pill case from United Health Care, or even a small squishy foam potted sunflower decoration from Sunflower. The setup reminded me of a job fair, or publishers hawking books at an academic conference. As I walked from one table to another, looking over the items, representatives from each MCO asked me if I had received my enrollment material in the mail for KanCare. I told them each 'no,' not letting on that I was a researcher, and they said to let them know if I had any questions. They were well-dressed, friendly, and seemed eager to help. I could not help but notice at one point, though, what seemed to be the scent of alcohol coming from one of the MCO

representatives. Either it was strong cologne or martinis. I just could not be too sure. Meanwhile, I noticed several people filling tote bags that each MCO handed out with goodies from each table. They were free, so why not? I grabbed some myself. The little squishy sunflower was too tempting, and who could turn down a free pen and notepad? I was trying to fit in.

The next event I attended, which was in Lawrence also, was a similar presentation for health care providers, but it was a little more intimate. The meeting was held at a large restaurant/event space. There was food for attendees, and we all sat around tables that could fit about eight people. I was not sure who all was in attendance, in terms of their professions. I sat at a corner table where I could see the whole room. We ate our meals, and then the presentation began. This meeting took place in 2013 after implementation, and many of those present expressed concerns about problems they were experiencing, such as delayed reimbursements and denied claims. State officials spent a lot of time trying to explain why providers were experiencing these problems and how they were being resolved. There was a lot of anger and skepticism in the room from the tone of people's voices when asking questions or making comments. This meeting in particular informed some of the questions I asked of providers in interviews.

I attended a third meeting for consumers in Lawrence, which was part of the series in February 2013, and it was markedly different than the other two. This meeting entailed individualized consultations with consumers by officials from the Kansas Department of Health and Environment, the Department of Disability and Aging Services, the KanCare Ombudsman, and an MCO representative in which consumers could express their concerns about their new KanCare plans, ask questions, or seek resolutions to problems they experience. A university researcher was also conducting short surveys with consumers who attended, which seemed to be

directed at their satisfaction with KanCare. I could not be too sure, as I could barely hear the researcher speaking and I did not ask (though in retrospect, I wish I had). After entering the room, I sat down at a small table by myself. I was approached by two women, one from the state and another representing the MCOs, and I informed them that I was conducting research on Medicaid reform. They both seemed intrigued at what I was doing. The insurance company representative spoke candidly to me and said patients need to take more personal responsibility for their health care, while the state official said encouragingly that taking a scholarly look at KanCare was “interesting.” I forced myself to sit there for an hour, which made me feel uncomfortable. I saw only three consumers, one of whom was an older man who identified himself as having a disability. He talked at length to the KanCare Ombudsman, James Bart, who was friendly, empathetic in his demeanor, and listened intently, about transportation problems the consumer said he encounters. He said that he likes to walk around The University of Kansas campus for his health, but because that sort of activity does not count as a doctor's visit, he has difficulty securing a transportation service to take him there. This event emphasized specific individual personal troubles and what individuals could do to resolve them. It seemed to me the personal attention to individual problems might be appealing to some, but I wondered about the efficacy of this sort of event given how few people attended during the one hour I was there.

The last public event about KanCare I attended was one organized by private citizens in Lawrence for members of the community. It was held in a meeting space at a church. There were about a dozen individuals there, including a member of the press and a state legislator, John Wilson, Democrat from Lawrence. The moderator provided an opportunity for individuals to speak, raise questions for discussion, or just make comments. The legislator spoke up in opposition to KanCare, said a few words, and left only to be followed out the door by the

journalist. After the event concluded, I spoke with a few of the individuals present just to get a sense of what they thought about KanCare. I mentioned that I was doing research on it, and each person I met responded positively. It was early in the reform, but people did seem genuinely concerned. One woman raised questions about how the MCOs could profit and not cut services or payments to providers, while another woman, who spoke up several times, was concerned about continuity of care, being able to see her current doctors. A couple who had a son with a disability was concerned about potential losses of services. What I gleaned from this event was that there was confusion and skepticism among consumers, their families, providers, and policymakers. I needed to look more in-depth to understand what the people were feeling and why.

## **Data Collection**

### *Interviews*

I used semi-structured interviews (see Appendix A, B, and C) and analyzed documents to answer the research questions. In interviews with KanCare consumers, I sought to learn about their needs, their health and socio-economic status, what they knew about KanCare and how, what informed their health care decisions, their health and social care related experiences, and their hopes and fears about KanCare. I talked with providers to learn more about the implementation of KanCare, their experiences under the new system in relation to the old, their views on KanCare, and their hopes and fears about it. I interviewed policymakers to learn more about the politics of KanCare, why KanCare was enacted, legislative oversight, and the evolution of the new program. The provider and policymaker interviews and document analysis contextualized the KanCare consumer voices, providing a 'thick description' of KanCare and what informed the experiences and views of the participants. Interviews lasted about one hour,



though an interview with two consumers simultaneously lasted nearly three hours. Participants I interviewed in person gave informed consent by signing an informed consent form, whereas I clearly explained their rights to those I interviewed over the phone after which they provided informed consent. I used a digital voice recorder in every interview (with their permission) and took notes with pencil and paper. The University of Kansas Human Subjects Committee - Lawrence Campus approved the study.

### *Documents*

For the document analysis, I created a list of 62 documents (see Appendix D) that gave voice to the state of Kansas and to a health care consumer advocacy organization, Kansas Health Consumer Coalition. I visited state of Kansas websites, including the Kansas Legislature, the KanCare website, and other agencies, such as the Kansas Department of Health and Environment and Disability and Aging Services, and I visited the website of Kansas Health Consumer Coalition. On the Legislature website, I searched for KanCare Legislative Oversight Committee hearing transcripts from 2013 and 2014. I selected specific webpages on the KanCare website that included information about KanCare, question and answers for consumers and providers, the MCOs, the MCO pay-for-performance measures, services and benefits, official documentation the state sent to the federal government when applying for permission to implement the reform (e.g., the 1115 demonstration waiver), KanCare advisory board meeting transcripts, KanCare working group minutes, public service announcement transcripts, and state agency reports about Medicaid before and after the implementation of KanCare. I searched for “KanCare” on the Kansas Health Consumer Coalition website, and made a list from every third search result. I selected every five search results, eliminated duplicate documents (i.e., content was about the same topic). I then downloaded copies of web pages and saved them as PDF files, or I

downloaded copies of documents from websites as PDF files. To make some of the documents searchable, I turned compatible ones into readable formats using Adobe Acrobat Pro to facilitate analysis in NVivo.<sup>26</sup> I loaded all documents into NVivo, and saved all files, including interview transcripts, in multiple locations that were secure. I organized all documents by type (e.g., letter, testimony, etc.). I created two lists: one for the state and one for advocates. The documents captured key voices of KanCare politics.

I chose to focus only on one advocacy organization, Kansas Health Consumer Coalition. I did examine others informally and do mention them briefly in the analysis for context. Because this organization advocated for health care consumers in general, unlike other advocacy organizations that focus on specific populations, I felt that they would best reflect the broadest interests of Medicaid consumers in Kansas. This was important, as the consumer interviews were not directed to any specific group. This way, the voice of advocates could parallel, somewhat, those of the consumers I would interview. Also, it was a practical decision, as other organizations did not have nearly as many documents available to analyze.

I also reviewed media accounts of KanCare that specifically targeted voices of the state and advocates to contextualize the data and confirm themes derived from the analysis. I found those articles by searching the website of the Kansas Health Institute News Service<sup>27</sup> using the keyword “KanCare.” I used these resources for direct quotes of policymakers and advocates that related specifically to themes from the analysis of state and advocacy group documents. These articles were not part of the actual content analysis, per se.

## **Data Analysis**

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<sup>26</sup> QRS NVivo 10 for Windows.

<sup>27</sup> <http://www.khi.org/news>

The coding scheme for interviews and content analysis followed an iterative inductive approach that allows for patterns to emerge from the data and the development of theory (Glaser 1965: 437). Coding was open, i.e., carefully reading through a few early interview transcripts to develop an initial coding scheme, and then refining the coding based on subsequent interviews and multiple “readings” of the texts. Such systematic and transparent coding helps avoid a ‘methodological black box’ resulting in the questionable validity that often times comes from inductive coding schemes (Matthes and Kohring 2008). After each interview, I adjusted the interview schedule to tap into themes that emerged from an initial analysis of the data. I also reworded a few questions to make them less confusing to participants. After the last interview of each group of consumers, providers and policymakers, I read through all interviews again, noting new themes, determined some themes to be sub-themes of larger more general themes, and I combined those subthemes into general themes to focus the analysis. I transcribed interviews within NVivo, and I coded all interview data and analyzed them using NVivo.

I conducted a qualitative content analysis of documents, which Hsieh and Shannon (2005: 1278) define as “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns.” It is a systematic means for deconstructing “naturally occurring” texts to uncover underlying meanings (Bauer 2000: 147). The qualitative analysis began by reading through each document carefully. I looked for and noted recurring themes. After comparing instances of each theme, I determined some to be subthemes of larger, more general, themes. I combined the ‘sub themes’ into the more general themes to focus the analysis. Themes I found in the state documents and the advocate documents that were similar determined the political discourse. For the themes that emerged in state documents that did not parallel themes in the advocacy documents, and vice

versa, I did not include in the analysis, as I was trying to capture a discourse about common issues. I coded all documents and analyzed them using NVivo.

## CHAPTER 3

### The Politics of KanCare

#### **Introduction**

The purpose of this chapter is to understand what KanCare is, and how it was enacted despite the contentious politics around it. Contentious politics have shaped health policy over time, but what is not clear is how these politics have shaped Medicaid at the state level, and how advocacy organizations have played a role. An analysis of the political discourse around KanCare revealed a legitimization process by which proponents of KanCare justified reform by using a crisis discourse around the state budget, stigmatizing the poor as irresponsible, and claiming successes at the earliest stages of implementation. KanCare critics responded by challenging the crisis narrative, calling for more public responsibility, and highlighting problems of implementation, thereby questioning KanCare's legitimacy. The resulting debate on the location of the responsibility for care influenced the implementation of mechanisms of public responsibility. I used documents, interviews with policymakers, and participant observation to construct and explore the political discourse between proponents of KanCare and its critics along three central themes of a need for reform, accountability, and success. It was through these three themes that the categories of proponent and critic emerged. For each theme, I compare the voices of proponents to those of critics to reveal a dialog of competing voices. I conceptualize competing claims as dynamic cultural and political structures within which public messages about KanCare are framed and are the discursive means by which power contestations occur between the state and advocates in the policymaking realm. For the purpose of this study, the Governor's and Lt. Governor's office, the Kansas Department of Aging and Disability Services,

the Kansas Department of Health and Environment, the Department of Children and Families, which works with persons with disabilities who receive Social Security Disability Income, a state public information officer, and a conservative Republican legislator are the proponents of KanCare. This group may not necessarily represent the views of everyone that supports KanCare, but they do provide meaningful insights into what proponents think about KanCare and why and how it was enacted. The critics were the Kansas Health Consumer Coalition (KHCC), which is a health care consumer advocacy organization, and three legislators I interviewed. Including policymakers' voices, while they do not speak for all legislators, adds depth to the analysis by showing that even within the state, Medicaid reform is debated. A brief examination of the political context at the end of the chapter demonstrates that KanCare reflects a broader tendency towards devolution of responsibility for care in Kansas, which, as I will discuss in the next two chapters, has implications for consumers and the delivery of health care in Kansas. Overall, KanCare remains a contentious policy that continues to engender skepticism but not outright opposition by organized publics.

While it seems intuitive that proponents would frame KanCare as necessary, a step towards accountability, and successful, and that its critics would disagree, the legitimization process shows that the contentious nature of KanCare politics was not one of diametrically opposed interests, as I had anticipated. Critics, for the most part, were more concerned for the welfare of consumers and were willing to see KanCare through than to oppose KanCare outright. KHCC in particular worked with the state to shape KanCare into a program that was beneficial to consumers by offering a moderate voice for publics in the development of KanCare. Acting somewhat as a 'watchdog,' they continuously called for accountability and transparency in the reform process and for independent, public oversight of KanCare. KHCC used the institutional

means available to it to give voice to consumers, including participating in various state-organized workgroups and legislative hearings around Medicaid, but aside from a few media statements, KHCC kept its action within the boundaries of the state.

I turn now to an analysis of the three themes that emerged from the data. I use quotes from documents and interviews with policymakers to illustrate each theme. I put the name of documents and their origins in footnotes.

## **A Need for change**

### *Proponents*

Why was KanCare enacted? The story begins in 2011 after the new governor, Sam Brownback, took office. He declared in a letter<sup>28</sup> to the federal Secretary of Health and Human Services that “[g]iven the unyielding budget constraints we face, *we have no choice* but to make significant changes in Kansas’ Medicaid program” (emphasis mine). Kansas was facing a \$200 million budget deficit in January 2011, and rising enrollments and cost would continue to be a problem (Appendix E). The state had to do something about Medicaid immediately. The need for change narrative became apparent in many of the documents and interviews with proponents of the reform. “Kansas faces major challenges in its Medicaid program that require swift and effective policy changes to continue serving vulnerable Kansans.”<sup>29</sup> If Medicaid was to continue to help low-income persons in Kansas, the state had no alternative but to reform the program. With “major challenges” that needed a “swift” response, it seems as if the state was facing a crisis. Kansas needed to act now, because “governments are slowest to adapt to change,” said Billy, a public information official with the state, in an interview. The new administration had to

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<sup>28</sup> Original letter. ([http://media.khi.org/news/documents/2011/03/10/Health\\_Care\\_Waiver\\_Request\\_Letter.pdf](http://media.khi.org/news/documents/2011/03/10/Health_Care_Waiver_Request_Letter.pdf)).

<sup>29</sup> “Executive Summary. KanCare: Reinventing Medicaid for Kansas” ([http://www.kancare.ks.gov/download/KanCare\\_Executive\\_Summary.pdf](http://www.kancare.ks.gov/download/KanCare_Executive_Summary.pdf)).

push for action. Change was imperative, but why specifically? And what should the change entail?

Driving the need were concerns over cost. The cost of Medicaid was too high and growing, Kansas was facing a budget shortfall, and health care costs in general in the U.S. were a problem. “In the decade leading up to KanCare, the annual rate of Medicaid growth was 7.5 percent.”<sup>30</sup> Billy reiterated what the Governor said in his letter to the federal government. “There was a \$200 million budget shortfall in Medicaid when the Governor came into office.” Thus, something had to be done so that the state could make ends meet. Along with the budget problem, there was a concern over increases in health care costs and spending nationally as a driving factor in the need for change in Medicaid. It was a topic of the first Advisory Council meeting. “Dr. Mosier discussed the relevance of health care reform initiatives, including at the national level, and the importance of health reform to Kansas.” As Scott, a conservative Republican legislator, told me in an email

[. . .] growth in health care spending was drastically outpacing growth in enrollment. This phenomenon was not unique to Kansas. As you well know, one of the largest discussions across the country right now is the trajectory of our health care system and our ability to sustain it for future generations.

To deal with these problems of budget and cost, “[t]he Administration committed to transforming Medicaid rather than implementing draconian cuts,”<sup>31</sup> according to Lt Governor Jeff Colyer in the first of a series of KanCare Advisory Council meetings in 2012. The state would not cut benefits or reimbursement rates, as has been the experience in other states. No matter what, though, proponents contended that reform had to happen. The Governor's office argued that a redesign of Medicaid in Kansas was necessary, because the program was too

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<sup>30</sup> “KanCare Advisor, March, 2014” ([http://www.kancare.ks.gov/download/FEB\\_24\\_2014\\_KanCare\\_Advisor.pdf](http://www.kancare.ks.gov/download/FEB_24_2014_KanCare_Advisor.pdf))

<sup>31</sup> KanCare Advisory Council Meeting Minutes of March 29, 2012.



costly. Budget troubles were imminent. Cost was a dominant theme in the data. Cost of Medicaid, or cost growth, was the key problem policymakers wanted to resolve through transforming Kansas Medicaid. In other words, for proponents, the need for change in Medicaid was a need to save money.

Costs seemed to be the top concern of policymakers. The Brownback administration contended that the only way to cut nearly \$400 million of Medicaid spending, while also improving health outcomes and the quality of care, was to “[get] away from this 1960s, fee-for-service model and into newer models.”<sup>32</sup> Such models would require a fundamental change in how Medicaid was structured in Kansas. Scott concurred and felt a similar sense of urgency to reform Medicaid. He saw that with the impending budget troubles, the growth in health care spending, and the increased costs of Medicaid, solving these problems

requires doing something different than what we have done in the past. Reforms that seek to increase caseload volume, spend more money, cut services or reduce provider rates are all temporary solutions for a long-term problem. Reforms that don’t address the structural flaws in the system, like care fragmentation and payment structure, is equivalent to rearranging chairs on the deck of the *Titanic*.

Medicaid was a sinking ship, and without significant fundamental change, it would drag the state down in its wake. The need for change was imperative. How, then, could Kansas transform its Medicaid program quickly, in response to the crisis, but not harm consumers or providers in the process? The state sought input.

During the summer of 2011, the state hired Deloitte Consulting, paid for by grants from non-profit groups in Kansas<sup>33</sup>, who organized “[t]hree Public Forums held across the State, a

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<sup>32</sup> McLean, Jim. 2011. “Governor-elect says “re-design” initiative will have two-fold objective of lowering costs and improving services.” *KHI News Service*. Retrieved July 4, 2014. (<http://www.khi.org/news/2011/jan/03/brownback-agenda-include-medicare-reform/>).

<sup>33</sup> The Health Care Foundation of Greater Kansas City, Kansas Health Foundation, REACH Healthcare Foundation, Sunflower Foundation and the United Methodist Health Ministry Fund.

public input web-based survey, population-specific Stakeholder Workgroup conference calls, and a final Wrap-up Forum.”<sup>34</sup> Members of the community, including advocates, consumers, and concerned citizens, could voice their ideas about how to reform Medicaid. The four major themes that emerged from the public input according to the consultant’s September 2011, report were

- Integrated, Whole-Person Care,
- Preserving and Creating a Path to Independence,
- Alternative Access Models, and
- Utilizing Community Based Services.

Some of the stakeholder feedback in these meetings included suggestions relevant to the final design of KanCare as a fully privatized Medicaid system. For example, some said that the “disabled population should have the opportunity to enroll in managed care plan. This would save money and potentially increase access.” Others said that the state should “develop a risk based capitated managed care model.” One of the problems with this report is how the feedback summary was organized. The author of the report does not indicate who said what, but since the report was created for proponents of reform, these sorts of statements would seem favorable to those who wanted to further privatize Medicaid or bring more consumers under managed care and legitimize their ideas.

Based on stakeholder input, the consultant made various recommendations on how to reform Medicaid. Several of the recommendations it made could be implemented in a “fee-for-service or managed care environment,” according to the report. This meant that the consulting company hired by the state, and paid for by non-profits, to facilitate collecting ideas for reform did not necessarily promote one way to organize Medicaid over another, though managed care

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<sup>34</sup> “Kansas Medicaid: Design and Implementation of a Public Input and Stakeholder Consult Process” ([http://www.kancare.ks.gov/download/KS\\_Public\\_Input\\_and\\_Stakeholder\\_Consult.pdf](http://www.kancare.ks.gov/download/KS_Public_Input_and_Stakeholder_Consult.pdf)).

options were cited more often than fee-for-service. It is interesting, though, that fee-for-service solutions were mentioned. As an aside, it was out of discussions within these groups that the name “KanCare” eventually emerged.

Interestingly, “everything [was] on the table” for strategies to redesign Kansas Medicaid.<sup>35</sup> There had been much talk about turning Medicaid into a 'block grant' program,<sup>36</sup> which was referred to as a “global waiver” in the 2011 “Reinventing Medicaid in Kansas Executive Summary.” A block grant is essentially a no-strings-attached lump sum of money given to a state by the federal government with which it can spend on a program, in this case Medicaid, in any way it sees fit. For instance, a block grant would allow Kansas to curtail a provision of the Patient Protection and the Affordable Care Act that requires states to maintain eligibility standards and services at 2008 levels, and do whatever it wants. The state could cut eligibility levels, reimbursements, or services, or a combination of strategies to cut costs. Regardless of what the state would do to reform Medicaid, it would be done through the market, because, according to Billy, a KanCare public information official I interviewed, “the market has all the innovative solutions.” Turning to the market was the way to resolve the crisis.

Proponents repeated the change mantra at every turn, but not just any change. Not just any solution would do. As the governor's remarks indicated, change had a specific flavor. The “newer models” are those that involve outsourcing the administration of Medicaid to private organizations, emphasizing consumer choice, and giving states greater flexibility in determining eligibility, reimbursement, and services. Managed care was the solution of choice. It was a

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<sup>35</sup> McLean, Jim. 2011. “Colyer says all options are on the table for remaking Medicaid.” *KHI News Service*. Retrieved July 4, 2014 (<http://www.khi.org/news/2011/mar/07/medicaid-policy-options/>).

<sup>36</sup> Mclean, Jim. 2011. “Brownback joins other GOP governors in call for Medicaid block grant.” *KHI News Service*. Retrieved July 4, 2014. (<http://www.khi.org/news/2011/mar/10/brownback-joins-other-gop-governors-call-medicaid-/>; [http://media.khi.org/news/documents/2011/03/10/Health\\_Care\\_Waiver\\_Request\\_Letter.pdf](http://media.khi.org/news/documents/2011/03/10/Health_Care_Waiver_Request_Letter.pdf)).

market solution to health care. Moreover, it is an “economically rational” solution, as one of the five Medicaid Transformation Principles implies.<sup>37</sup> A presentation given by the state in August 2011, on the public input and stakeholder consultation process states that “Economic Rationality means everyone needs to feel the link between outcomes and costs.” On the same page, the document compared the current structure of Medicaid spending to a Communist model: “Medicaid Pricing/planning structures are very similar to Soviet military economics.”<sup>38</sup> Why the choice of the word “Soviet,” and what did the Lt Governor mean by this analogy? It would not be the first time a conservative voice used the specter of socialism to deride publicly-financed and administered health care. It is clear, though, that the “newer models” would not be Soviet-style.

Based on these principles, “[t]he state will leverage private sector innovation to achieve public goals by issuing a Request for Proposal targeting three statewide KanCare contracts.”<sup>39</sup> This is when the state looked to the market for its “innovative solutions.” Was it just that the market had the answers, or could there have been a more complex reason for choosing more private, for-profit managed care? In a KanCare Consumer and Provider Workgroup in 2013 explaining why Kansas looked to the market for solutions, “[Medicaid Director] Dr. [Susan] Mosier stated there is a trend for Medicaid nationwide to go to a Capitated Risk Based Managed Care System. She stated that 50% of the states have indeed adopted this system.” Because other states were doing it, Kansas should, too, which is similar to the policy diffusion argument made

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<sup>37</sup> “Kansas Medicaid: Design and Implementation of a Public Input and Stakeholder Consult Process” ([http://www.kancare.ks.gov/download/KS\\_Public\\_Input\\_and\\_Stakeholder\\_Consult.pdf](http://www.kancare.ks.gov/download/KS_Public_Input_and_Stakeholder_Consult.pdf)).

<sup>38</sup> “The Medicaid Reform Public Input and Stakeholder Consultation process” PowerPoint presentation, August 21, 2011 ([http://www.kancare.ks.gov/download/Medicaid\\_Reform\\_Public\\_Forum.pdf](http://www.kancare.ks.gov/download/Medicaid_Reform_Public_Forum.pdf)).

<sup>39</sup> “Executive Summary. KanCare: Reinventing Medicaid for Kansas.”

by Miller and Banaszak-Holl (2014). As such, “Kansas has the first fully capitated model, which will bend the cost curve,” Billy stated.

In 2012, the state organized several groups for more public input: KanCare Advisory Council, Consumer and Specialized Issues Work Group, Provider and Operational Issues Workgroup, and four external Stakeholder Workgroups for providers, MCOs, advocates, and “specialized health care and network issues. Out of these, I focused on three groups in which consumer publics had a voice, which were the Advisory Council, the Consumer Issues Workgroup, and the external group for advocates called the Member Involvement and Protections Workgroup. Also present at many of these workgroup meetings were representatives of the three MCOs. “The Governor's KanCare Advisory Council was formed in March 2012 to provide the Administration with ongoing insight and recommendations on the implementation of KanCare. The Council meets quarterly. Additionally, the Council has invited other KanCare stakeholders to serve as members of two External Stakeholder Workgroups.”<sup>40</sup>

The main tenets of KanCare emerged in the KanCare Advisory Council meetings in 2012. “The goal of the Council is to help ensure that KanCare improves outcomes for all Medicaid groups.” “The key principles of KanCare include getting better results through integrated, coordinated care, looking at the whole person, planning ahead for funding cuts from the federal government, and helping beneficiaries reduce their dependence upon the system.”<sup>41</sup> KanCare is based on three criteria: improving quality of care, controlling costs, and “making sure we have long-lasting reforms that improve the quality of health and the quality of wellness for Kansans.”<sup>42</sup> Reform without incurring costs to the taxpayer was also a recurring theme in the

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<sup>40</sup> “Advisory Council & Workgroups.” Retrieved April 15, 2016 ([http://www.kancare.ks.gov/advisory\\_council.htm](http://www.kancare.ks.gov/advisory_council.htm)).

<sup>41</sup> KanCare Advisory Council Meeting Minutes of March 29, 2012.

<sup>42</sup> KanCare Approval Decision ([http://www.kancare.ks.gov/download/kancare\\_approval\\_decision\\_transcript.pdf](http://www.kancare.ks.gov/download/kancare_approval_decision_transcript.pdf)).

data. By improving efficiency, better coordinating Medicaid services and care, and encouraging Medicaid consumers to take more personal responsibility, KanCare will control the cost growth of Medicaid and improve health outcomes and the quality of care (Office of the Governor 2011) and save the state \$1.1 billion over five years (Brunner and Ast 2013). It will do so *without* reducing consumer benefits or cutting health care provider reimbursements, which are to remain at the November 9, 2012, level<sup>43</sup>.

As Billy told me in response to a question about how the state would save money under KanCare, “the idea is to find efficiencies in service delivery and implementation. You don’t have to spend more to get more. You can be more efficient and get better outcomes.” MCOs will increase efficiencies in the system through innovative practices and processes. They will better coordinate the care of consumers, especially those with complex health needs, by maintaining a consistent line of communication between care providers, the patient, and the MCO and ensuring the patient ‘gets the right care at the right time,’ thus increasing efficiency. MCOs are to encourage prevention and primary care over more expensive specialist care and emergency room visits to lower the cost growth of Medicaid, and encourage doctors to provide ‘evidence-based medicine’ and authorize only the care that is medically necessary as additional ways to control costs. One problem with controlling costs, though, is the risk of cutting services to consumers or reimbursements to providers, which has typically been the case in the past (Olson 2010), something KanCare is supposed to avoid. At the public forum for consumers I attended in Olathe in 2012, someone asked how MCOs would profit while lowering costs and not cutting benefits or reimbursement rates. The answer given by a state official was “the efficiency of the market.”

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<sup>43</sup> KanCare Provider Frequently Asked Questions. ([http://www.kancare.ks.gov/provider\\_faqs.htm](http://www.kancare.ks.gov/provider_faqs.htm)).

Efficiency of market actors was a recurring theme in how the state explained purported cost savings KanCare would bring. Treating the “whole person” or a “patient-centered approach,” was one of the four reform themes that emerged from the 2011 stakeholder consulting process, and was cited as another way KanCare would be more efficient and cost effective. An interesting exchange in a 2013 KanCare Workgroup illustrates this point and explains how the state would be able to control costs without cutting services (efficiency).

Q: How do we maintain costs once shifted to KanCare how are the costs going to be contained or services maintained? By not cutting services how do you save money?

A: Dr. [Susan] Mosier – By treating the whole person. Physical health as well as developmental or psychological issues. An example was given regarding controlling a person with diabetes. By controlling their eating habits, you not only control their sugar levels, but also their weight and possibly cholesterol and other levels. By doing all this you may save a consumer from becoming an amputee. We realize that moving to this format is long-term ways to reduce cost. In the short run, you may actually see costs go up, but in the long term, we see better health and better life as well as long-term costs reductions.

The idea is to dissolve barriers between various care silos (physical, mental, nutrition, specialists, etc.). It is reorganizing care, better coordinating care, not cutting it. That is, KanCare is about the efficient use of services. In the process, this more rational use of health care services in the short term prevents costlier problems in the long term. That is the theory maintained by proponents.

The language of rationality and efficiency echoes what Optumas, the health care consultant Kansas paid \$1.7 million to assist with implementing KanCare in 2012,<sup>44</sup> says on its website “[T]he purpose behind health care reform is now clear – to develop a healthy, productive economic engine, states and municipalities must have a healthy, productive workforce at the local level.” Their idea is to “blur the lines between existing payer sources in the market to eliminate artificial barriers that insulate all participants from the true cost of health care (both

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<sup>44</sup> Marso, Andy. 2012. “\$1M approved for KanCare waiver consultant in April.” *Topeka Capital-Journal*, August 7. Retrieved June 15, 2016 (<http://cjonline.com/news/2012-08-06/1m-approved-kancare-waiver-consultant-april>).

under-payment and over-payment) and cause individuals to make poor economic decisions about their health care.” Lastly, “by developing a more transparent, rational health care marketplace, excess health care costs, and opportunity will be transferred from those who don’t need it with no reduction in their productivity to those who desperately need it with a substantial increase in their productivity.”<sup>45</sup> For Optumas, health care is an economic issue, and this is basis of KanCare: a solution to an economic problem.

Documents and interviews suggest that the risk-based capitated managed care model was the only solution considered by policymakers, in light of the comments made by policymakers throughout 2011. I could find no evidence in the public documents I analyzed that shows a debate within any of the public forums on whether or not to use more managed care or continue using fee-for-service for some of the Medicaid population other than the mixed policy recommendations made by Deloitte. The Director of Medicaid Services stated that “[w]e believe KanCare is the answer for Kansans. It will help us provide integrated, coordinated care for our state’s most vulnerable citizens while keeping costs down.”<sup>46</sup> As the Governor proclaimed during a news conference announcing the federal government’s approval of KanCare in late 2012, “KanCare is truly what Kansas needs.”<sup>47</sup> Medicaid needed reform, and KanCare was *the* solution. I turn now to how critics responded to the need for change.

### *Critics*

The Kansas Health Consumer Coalition (KHCC) represents Medicaid consumers in general, not just specific constituencies (e.g., nursing home residents, persons with disabilities, elderly, and children). This group was one of the most outspoken groups that I came across in

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<sup>45</sup> “Why Health Care Reform.” Retrieved October 25, 2016 (<http://www.optumas.com/why-health-care-reform/>).

<sup>46</sup> “KanCare Advisor, 12/19/2012” ([http://www.kancare.ks.gov/download/Kancare\\_Advisor\\_12\\_19\\_2012.pdf](http://www.kancare.ks.gov/download/Kancare_Advisor_12_19_2012.pdf)).

<sup>47</sup> “KanCare Approval Decision” ([http://www.kancare.ks.gov/download/kancare\\_approval\\_decision\\_transcript.pdf](http://www.kancare.ks.gov/download/kancare_approval_decision_transcript.pdf)).



my initial research on KanCare. They made numerous public statements about KanCare through radio news programs, legislative testimony, letters to government officials, and their website and email listserv. As an organization that “advocate[s] for affordable, accessible, and quality health care for all Kansans” ([www.KHCC.com](http://www.KHCC.com)), they gave voice to thousands of Kansans who are uninsured or underinsured, or who receive Medicaid benefits. As an advocate for Medicaid consumers, KHCC was deeply concerned for the future of Medicaid in Kansas and, from the beginning, raised questions about the proposed reform. Their criticism began with proponents’ claim that change was necessary.

KHCC, and other critics, had a different take on the need for change narrative. They did not see a crisis as proponents argued. The economic reasons given for reform did not seem to warrant the response by proponents from their view. KHCC criticized the purported savings KanCare was to bring Kansas – one of the solutions to the budget deficit when Brownback entered office – and the data used to support claims of cost growth. Advocates were unsure if “savings of that magnitude were actually possible, [given] that Medicaid spending in Kansas is growing much slower than in most states, and that its services are currently under-utilized, rather than being overrun.” Furthermore, “while costs are on the rise, and the recent economic downturn has caused a surge in enrollment, Kansas still spends a smaller percentage of health care dollars on Medicaid than its neighbors.”<sup>48</sup> While the state of Kansas paid 30.4 percent of total Medicaid expenditures in 2013, it spent less than the national average for Medicaid as a proportion of total spending between both the state and federal government. In 2014, Kansas paid 43 percent, which is above the national average of 40 percent. The federal cost-share rate

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<sup>48</sup> KHCC. “KanCare: A Review” (<http://kshealthconsumer.com/>).

changes every three years to account for changes in the economy<sup>49</sup>. For comparison, the state that paid the least in 2014 is Arkansas (23%), and the states that paid the most were Virginia, Wyoming, New Hampshire, and Massachusetts (49%)<sup>50</sup>. I am cautious to compare Kansas to other states in this way, though, as spending proportions vary considerably for different reasons. More telling is the average annual growth rate of Medicaid spending per state. The average annual growth in Kansas Medicaid spending from 2007 to 2010 was 4.5 percent, which was below the national average of 6.8 percent. The rate declined from 6.0 percent between 2004 and 2007, which was far less than the growth rate in the 1990s of 11 percent (the growth rate between 2010 and 2014 was 3.2%, with a national rate at 5.2%).<sup>51</sup>

What these figures suggest is that the interpretation of Medicaid cost growth is important. The fact that it was growing slower just prior to Brownback's call for reform may not mean that the growth rate was declining as quickly as some policymakers might have wanted. Whereas, the decline in growth rate might have been sufficient for other observers to not consider it a crisis. Indeed, Michelle, a moderate Republican legislator, understood the need to "control cost growth," but that it was a "nationwide" problem, she said, and did not see it as a particular problem for Kansas exclusively as the crisis discourse might imply. Regardless, the feeling of some critics was that, as Nora, a liberal Democratic representative, said, Kansas is "stingy about health care." From her point of view, Kansas was not spending enough.

In response to the crisis discourse of proponents and the need to move on reform quickly, KHCC was concerned about how fast the reform process was going, fearing that the state would

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<sup>49</sup> "Financing & Reimbursement." Retrieved April 22, 2016 (<https://www.medicaid.gov/medicaid-chip-program-information/by-topics/financing-and-reimbursement/financing-and-reimbursement.html>).

<sup>50</sup> "Federal and State Share of Medicaid Spending, FY 2014." Retrieved April 22, 2016 (<http://kff.org/medicaid/state-indicator/federalstate-share-of-spending/#table>). When I began writing this chapter, the data available from this source was for FY 2013, but now only FY 2014 is available.

<sup>51</sup> "Average Annual Growth in Medicaid Spending." Retrieved April 22, 2016 (<http://kff.org/medicaid/state-indicator/growth-in-medicaid-spending/>).

not be able to meet its obligations to the federal government. Anna Lambertson, the director of KHCC, argued that “[t]he whole timeline is pretty quick [...] I think there are a lot of unanswered questions.” The speed of reform was an issue for critics from day one. It appeared in the first KanCare Member Involvement and Protections Workgroup in July, 2012. Part of advocates’ apprehension about the timing of reform was the immediate inclusion of persons with intellectual and developmental disabilities in managed care. This group is “not fit for the managed care model,” according to Michelle. Nora agreed. “I am concerned with the inclusion of the intellectual disability and developmental disability group in managed care. Is there a better way? What else is being managed?” Critics wanted the state to leave this group of consumers out of managed care, at least for a while, and keep them under the old fee-for-service system, because it worked, from their point of view. They felt that the new system could result in a loss of services, which would mean a marked change in quality of life for persons with disabilities. Indeed, some disability rights advocates were staunchly opposed to including this group in managed care. “They believed that insurance companies have no experience or expertise in providing day, residential, employment or in-home support services to individuals in the community.”<sup>52</sup> Advocates felt that the existing networks of private, public, and community resources should continue to provide care for certain vulnerable groups. In the August Member Involvement and Protections Workgroup, the minutes showed that “[d]isabilities consumers are delayed by 1 year from having to enter KanCare.”<sup>53</sup> This meant that consumers with intellectual and developmental disabilities would not be enrolled until January, 2014. Interestingly, the Centers for Medicare and Medicaid Services (CMS) temporarily halted the inclusion of this

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<sup>52</sup> Cottonwood. “Don’t Gamble with Our Lives.” Retrieved January 29, 2016 (<http://www.cwood.org/dont-gamble-with-our-lives/>).

<sup>53</sup> KanCare Member Involvement and Protections Workgroup 08-08-2012 2:00pm Minutes.

group until the state adequately responded to their concerns about, among other things, how consumer's needs are determined, provider capacity to meet consumer needs, what consumer's recourse is if a claim is denied, and the underserved wait list.<sup>54</sup> Thus, the state was not able to include this group in managed care until February, 2014. While this might be viewed as a modest win for critics, it was not sufficient for some. The director of Interhab, a health care consumer advocacy organization for persons with developmental disabilities, stated

I'm extremely disappointed that the thousands of hours spent by families, providers and advocates didn't count for more at CMS [. . .] The philosophy of this (KanCare) program is a setback for the system we have for serving the disabled in this state and it will be a setback for some time. It places the interests of the bureaucracy above the interests of the people the bureaucracy was intended to serve and I think that's sad.<sup>55</sup>

As an aside, Shawn Sullivan, Secretary of Kansas Department of Disability and Aging Services in 2013, stated in the KanCare Advisor newsletter, “[u]nfortunately, there is an advocacy campaign with a lot of misinformation that has created heightened anxiety and fear for persons served as well as their family members and guardians.”<sup>56</sup> He went on to list “the facts” about the inclusion of disabilities groups in managed care. Even though enrollment in managed care for some consumers was delayed, the timing of reform as a whole was troublesome for critics. “Why was there no pilot program,” asked Holly. “Why the hurry?”

Regarding the question of there being a pilot program, there was one proposed to curb spending by incentivizing consumers who expected to lose Medicaid eligibility due to an increase in income. It was intended to encourage consumers to not re-enroll for a specified time. Under the program, “up to 500 people” would receive “a debit card preloaded with \$2,000 for

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<sup>54</sup> CMS letter to KDHE Director Kari Bruffett. *KHI News Service*. Retrieved January 29, 2016 ([http://media.khi.org/news/documents/2013/12/27/KS\\_0224\\_R04\\_04\\_RAI\\_December\\_27\\_2013.pdf](http://media.khi.org/news/documents/2013/12/27/KS_0224_R04_04_RAI_December_27_2013.pdf)).

<sup>55</sup> Shields, Mike. 2014. “Feds approve KanCare DD carve-in.” *KHI News Service*. Retrieved January 29, 2016 (<http://www.khi.org/news/article/feds-approve-kancare-dd-carve-/>).

<sup>56</sup> “KanCare Advisor, May, 2013” ([http://www.kancare.ks.gov/download/KanCareAdvisor\\_5\\_10\\_2013.pdf](http://www.kancare.ks.gov/download/KanCareAdvisor_5_10_2013.pdf)).

health care expenses, renewable for three years if they forgo Medicaid eligibility.” KHCC responded by saying that people will use that money for out-of-pocket costs that will not go very far, and therefore will be of little utility to consumers. There was also a proposed pilot program for consumers with certain disabilities.

Advocates were also critical of the way in which reform was to be structured through the increased use of managed care. KHCC said, “a one-size-fits-all method will be insufficient to meet the diverse needs of beneficiaries in our state.” Additionally,

most of Kansas’s Medicaid population is already in a managed care system. The populations to be added are also the most expensive to cover, the elderly and people with disabilities. It is, as yet, unclear whether a managed care system is suited for these populations, as they require much more long-term and non-clinical care, areas traditionally outside the expertise of health insurance companies.<sup>57</sup>

Highly rationalized care, or the “whole person” or “patient-centered” approach proponents espouse, demands a ‘one-size-fits-all’ model, but this did not sit well with critics. Michelle stated that she was “uncertain that Medicaid managed care will work,” especially for persons with disabilities. She did not know if it would “facilitate what is best for people.” The problem, Michelle said, was that Kansans were “not given a choice.” However, some of the criticism about the increased use of managed care was not about if it could do the job or not. Holly said that she was “not opposed to Medicaid managed care; I am against out of state for-profit and an all-in and all at once approach” to including all consumers in managed care. Moreover, the purported savings of KanCare should “stay in Kansas.”

Critics did not perceive the same crisis that proponents of KanCare claimed in 2011 and 2012, but they knew Kansas “had to do something,” as Holly declared. They understood costs were a problem, but were not convinced that the increased use of managed care would solve the

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<sup>57</sup> KHCC. “KanCare: A Review.”

problem. “Can a health insurance company do” all of what the state claims, asked Nora? They did not understand the rush to reform. Nor were they convinced KanCare would be the best thing for consumers, especially those with certain kinds of disabilities. As far as the need for change is concerned, proponents and critics did not see eye to eye. The former espoused a sort of crisis discourse, while the latter framed the need for change in terms of caution. Critics were not against change, per se, or even against managed care entirely. They just did not want the change that was proposed, how it was justified, or the speed at which change was occurring. Critics preferred a more gradual change based on evidence of what actually works, and change that is transparent and accountable. Another source of contention for proponents and critics was the issue of accountability.

## **Accountability**

### *Proponents*

Another theme common to proponents and critics was that of accountability. For proponents, accountability entailed consumers being more personally responsible for their care, managed care organizations being more responsible for quality of care, legislative oversight of KanCare, and being transparent in the reform process. Out of four subthemes of accountability that emerged in analysis of state documents and proponent interviews, the personal responsibility discourse was the most prevalent.

‘Personal responsibility’ first appeared early in 2011 in the Kansas Medicaid Reform Objectives issued by the state: “Expectation of personal responsibility for active participation in health care maintenance,” and “Emphasis on Medicaid as a short-term option for coverage.” The points indicated that people, whether poor or disabled, should be seeking care through other means regularly, but only Medicaid when necessary. Personal responsibility means not relying

on the government for assistance unless one absolutely needs it. The Reform Objectives do not indicate when that need occurs, however; rather the Objectives assume that Medicaid is an option for some people to use under certain circumstances.

Personal responsibility again appeared on state agency PowerPoint presentations before “KanCare” became the name of the new program: “Our vision is to serve Kansans in need with a transformed, fiscally sustainable Medicaid program that provides high-quality, holistic care and promotes personal responsibility.”<sup>58</sup> This theme was actually in the policy recommendations from Deloitte Consulting in 2011.

Empowering Medicaid consumers to make better health care decisions can be a key strategy in the potential transformation of the Kansas Medicaid program. Traditional approaches to Medicaid redesign and cost containment have focused on incenting providers and other entities like MCOs to improve health outcomes and reduce the cost and frequency of care. Limited attention has been focused on how to more effectively engage Medicaid consumers in managing their health needs in a way which is both cost effective for the health care system and beneficial to the health status of the consumer.<sup>59</sup>

Here, personal responsibility is the responsibility of the consumer, not their health care provider or, I would argue, their paid or unpaid caregiver. The individual is expected under KanCare to take a more active role in their care, which assumes they have not been doing so already. This expectation devalues any work that individuals already do to care for themselves in the ways they are able.

In 2012, the Request for Proposals issued by the state to potential MCOs says that there is an “expectation of personal responsibility for active participation in health care maintenance,” just as it is stated in the official reform objectives. MCOs must “encourag[e] members to participate in decisions regarding their care and educat[e] them on the importance of doing so.”

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<sup>58</sup> This statements appeared in the footer of many PowerPoint slides presented by state officials at KanCare legislative oversight committee hearings.

<sup>59</sup> “Kansas Medicaid: Design and Implementation of a Public Input and Stakeholder Consult Process.”

Expecting consumers to do more must be enshrined in how the MCO organizes care. Personal responsibility entails taking advantage of incentives and using information in the way MCOs would want. What if a consumer does not feel incentivized? What if the consumer thinks the information is not useful? I address these questions in the next two chapters.

The personal responsibility theme is evidenced in the issue of consumer choice. The fact that consumers did not have a choice of health care plans was cited by the state as a problem for controlling costs.<sup>60</sup> Prior to KanCare, consumers who were enrolled in managed care had two choices of MCO. Others were enrolled in fee-for-service. KanCare emphasizes the freedom it gives Medicaid consumers to choose: to choose their own health insurance plan and to choose their own doctor. As for choice of plan, each MCO provides its own Medicaid plan that offers different value-added services and provider network. Consumers can select a plan based on the services provided and if their preferred doctor accepts a given plan. One of the three KanCare MCOs, Sunflower Health Plan<sup>61</sup> advertises on its website that it is “adding new providers to our network *every day!*” (italics original) so that consumers have greater choice. Another MCO, Amerigroup, says, “[m]ore doctors, clinics and hospitals join our network every day.”<sup>62</sup> This does not mean that more providers overall are accepting KanCare. Rather, it means that providers that had accepted Medicaid before KanCare was enacted are now signing up with Amerigroup or Sunflower, but not all of them have so far. Consumers will not have more doctors from which to choose. Consumers can select the plan their health care providers accept and which meets their needs. Services encourage prevention, which in theory, reduces the overall

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<sup>60</sup> Kansas Department of Health and Environment legislative testimony April, 2013.

<sup>61</sup> “Find a Provider.” Retrieved October 25, 2016 (<http://www.sunflowerhealthplan.com/for-members/find-a-provider/>).

<sup>62</sup> “Why Amerigroup? Because We’re Different.” Retrieved October 25, 2016. (<https://www.myamerigroup.com/ks/Pages/welcome.aspx>).



cost of Medicaid and improves consumers' health. Thus, consumers can choose the plan that they feel works best for their situation, needs, and wants. In fact, some consumers did switch their plans in that initial 90-day open enrollment period. Each MCO received approximately 120,300 members in the initial enrollment, but after the 90-day choice period, the distribution changed slightly with Sunflower receiving a greater proportion of consumers (Sunflower: 36.7%; Amerigroup: 32.1%; and United Health Care: 31.2%). Personal responsibility, thus, is the consumer taking advantage of the freedom to choose the best course of action for their health.

Related to the consumer choice issue is how proponents wanted to make sure consumers had sufficient information. The “[p]urpose is to get information out that members will need to make appropriate decisions”<sup>63</sup> The state proposed numerous strategies to reach consumers, including direct mailing, public forums, and a website. One of the methods, the public forum, was an interesting experience that I observed on three occasions. The presentations at the two large forums in Olathe and Lawrence were informative, but said little more than what one could find on the KanCare website. The meetings implied that if consumers have information about the changes to Medicaid and about the three health plans, they can make informed decisions about their health care. No change was one of the recurring themes of the public forums for consumers. It sounded like a selling point, as if the state was trying to “sell” KanCare to consumers. According to my field notes from both of these meetings, attendees were repeatedly told by state officials that they would experience no changes. During the question and answer session after the formal presentations, the most common question I heard was 'what will change for me?' One problem was that about half of the audience left after the formal presentation, thus fewer people were around for the more interactive portion of the meeting. Several people had questions, but

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<sup>63</sup> KANCARE Workgroup Member Involvement/Protections July 13, 2012, 10:00 am, meeting minutes.

again, they all tended to be about what would change about their services. While at the meetings, I felt like I was being talked *to*, rather than being talked *with*. I was intrigued to find that someone else had articulated just such a concern at one of the Workgroup meetings in 2013:

Q: One of the critiques we have of the tours that were held previously is that there was a lot of people being talked to rather than having an interaction between audience members and speakers. Are you going to reformat those tours?

A: Ren [Mullinex, Public Information officer] indicated they have received similar feedback from several regarding this same topic. The direction we are heading with this tour is the same as with the pilot tour in that we will be trying to keep it interactive. We would like for booths to be set up for more of a Q&A so attendees may actually meet their provider rep. In that region, meet the consumer rep in that region. He stated he agreed completely with the comments that have been made

After these large meetings were held, I attended a third meeting, which was much smaller in scale and more one-on-one. Though I described this meeting in Chapter 2, the one observation I made at that meeting relevant to the issue of information was that only three people showed up in the one hour I was present. I was there from 6:00 PM to 7:00 PM. Though the scale was small, individuals who did attend had an opportunity to discuss their problems and concerns with their MCO, the state, and the Ombudsman. This format made me think about the difficulty of reaching the Medicaid population. While the state did make efforts to get the word out, which I will discuss in more detail in the next chapter, these efforts made me think: is simply telling people what is happening with Medicaid sufficient for them to comprehend the changes? At the small one-on-one meeting, could the presence of so many officials have been overwhelming or intimidating to consumers? I felt a bit overwhelmed, and I was just there to observe. Regardless, personal responsibility also means taking advantage of information that is given and using the resources one has available.

With sufficient information and incentive, the assumption KanCare proponents make is that people will choose the most cost effective care, or care that saves the state money, and when they do, they should be rewarded. The Lt Governor said as much in a 2011 presentation.

Personal Health Decisions have the biggest impact on quality of life. Need to align Medicaid to reward personal responsibility—just as private insurers do. Example: Reward patients who quit smoking, improve obesity, etc. Example: Reward patients who actively manage their own healthcare, take their medications, etc.<sup>64</sup>

There is no mention in any documents I found that explain what a “reward” should be, but KanCare MCOs are supposed to offer value-added services that incentivize personal responsibility. Through these services, among other things, they encourage consumers to seek primary care instead of going to the emergency room for treatment when they are sick. Reducing unnecessary emergency room visits is a reasonable objective, as emergency room care is costly. There were 130 million emergency department visits in 2010 nationally, up 34 percent from 1995, accounting for about 4 percent of all health care spending in the U.S (National Center for Health Statistics 2013).

Even with efforts promoting preventative care and encouraging people to use primary care first, Medicaid beneficiaries in general may still go to the emergency room (Kaiser Health News 2014). People go to the emergency room for various reasons, including insurance status, perceived severity of the condition, and availability of care (National Center for Health Statistics 2013), and if their care needs fall outside the typical work day of physicians, like Saturday morning at 3:00 AM, leaving people with little choice. Medicaid requires MCOs to pay for emergency care based on a “prudent layperson” standard, that is, care that a rational, reasonable person would consider a necessary emergency (National Center for Health Statistics 2013), but

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<sup>64</sup> Medicaid Reform Public Forum presentation, August 8, 2011.

this is difficult to objectify given how different people define what constitutes an ‘emergency’ (Derlet and Ledesma 1999). As note before, the rational actor assumption is problematic and does little to help understand how people actually deal with their health.

Related to the high costs of emergency room visits are readmissions to hospitals. The 30-day readmission rate for Kansas Medicaid prior to 2011 was about 10 percent, almost half of which is accounted for by low birth weight issues. Readmission costs are 50 percent higher than initial admission costs, but these costs are not driving the increased expenditures of Medicaid. Avoidable readmission rate is about 11 percent. These facts were discussed in late 2011 in a presentation by a “Medicaid Reform Data Workgroup” in a forum based on the Medicaid Reform Public Input and Stakeholder Consultation from summer 2011.<sup>65</sup> This group also presented data showing that the Kansas “Working Healthy” program reduces health care costs, but the growth of the program had been declining. They also presented findings that show “while home and community based services increases spending initially, eventually long term savings come from reduced institutional spending.” The presenter also stated, “AARP ranks Kansas as having the 6th highest nursing facility utilization per capita and the 4th highest HCBS utilization per capita for adults over 65.” The point of these presentations was to use existing data to show what changes policymakers might consider, indicating that reform should include work incentives, increased use of home and community based care, and ways to keep people from going back to the hospital. Implied is that consumers take on more responsibility for their care. They should get a job, seek in-home care services, and take appropriate action to prevent going back to the hospital. In other words, devolution of care responsibilities to consumers reduces

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<sup>65</sup> *ibid*

costs, and the MCOs facilitate this devolution, though it is not clear to me how that will be done at this point.

Another aspect of the accountability theme is MCO responsibility for quality of care.

Scott claimed that

KanCare has modernized our old Medicaid system in Kansas by realigning incentives through a pay-for-performance mechanism. There are 15 performance measures tied to health outcomes, and six tied to timely billing to providers, prior authorizations, etc. The State is withholding half a billion dollars from the three managed care organizations unless they meet the performance standards dictated by the State. As a result, this is the first time in Kansas history that the Medicaid program is being held accountable for the quality of care it provides and the cost at which that care is provided.

While I cannot verify independently that MCOs prior to KanCare were not held accountable, it is worth noting that MCO responsibility was a recurring theme, though not as much as personal responsibility. The state incentivizes MCOs to ensure their consumers receive the best care through pay-for-performance measures. If they do not meet or exceed the performance criteria,<sup>66</sup> then the MCOs will lose money.

The third aspect of accountability is legislative oversight. This form of responsibility appeared a few times in documents, and it was a notable component of the reform and implementation process. It is worth noting as a variation from the personal responsibility discourse. A press release in early 2012 by the Lieutenant Governor's office stated there should be legislative oversight of KanCare.

These proposed bills are an important part of continuing our accountability to the people of Kansas," Lt. Gov. Colyer said. "Legislative oversight will be key in accomplishing the objectives of KanCare that lead to improved delivery of health care to Medicaid consumers."<sup>67</sup>

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<sup>66</sup> "KanCare Program Medicaid State Quality Strategy." Attachment J to KanCare RFP, September, 2014 ([http://www.kancare.ks.gov/download/Attachment\\_J\\_State\\_Quality\\_Strategy.pdf](http://www.kancare.ks.gov/download/Attachment_J_State_Quality_Strategy.pdf)).

<sup>67</sup> "Lt. Gov. Colyer: Legislative Oversight Essential to Providing Highest Quality of Services under KanCare." March 15, 2012 ([http://www.kancare.ks.gov/download/KanCare\\_Legislative\\_Oversight\\_release.pdf](http://www.kancare.ks.gov/download/KanCare_Legislative_Oversight_release.pdf)).

Interestingly, in this same press release, is the statement: “KanCare will address the shortcomings in the current system through a unique model of care that holds the State of Kansas and three integrated care companies accountable.” In 2012, Republican Representative Robert G. Bethell pushed for a legislative committee to oversee KanCare. The result of his work was an 11-member committee named in his memory made up of five senators and six representatives.

Conservative Republican representative Scott explained that

As a legislator, I believe that it is important to continue enhancing our Medicaid system in a way that is accountable to the patient and to the taxpayer. Serving on the oversight committee puts me in a wonderful position to ensure that while we are pursuing such innovations, we are doing so in a responsible manner.

From his statement, he is serious about making sure consumers receive proper care and that the system is attentive to the needs of taxpayers, as well. From his point of view, making sweeping changes in Medicaid also means that the changes are handled with care.

A dimension of the public accountability theme is transparency of the reform process. “For more than a year, the Administration has been dedicated to a transparent process in remaking the state’s Medicaid program,” according to a press release in 2012.”<sup>68</sup> Moreover, “The public input and stakeholder consultation process validated the need for increased accountability in the services the state provides, and for a new level of investment in prevention, care coordination, and evidence-based practice.”<sup>69</sup> Officials created a variety of mechanisms to include the voices of stakeholders since the beginning of the process, including a series of workgroups, public forums, an advisory council, and daily stakeholder conference calls to address technical issues.<sup>70</sup> The state also formed a KanCare consumer advisory board that

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<sup>68</sup> Ibid.

<sup>69</sup> “Executive Summary. KanCare: Reinventing Medicaid for Kansas.”

<sup>70</sup> KanCare Advisory Council meeting minutes, January 8, 2013.

functioned to bring the voices of Medicaid consumers into the official policymaking structure. The advisory board only met a couple of times and was disbanded by the end of 2012 according to available transcripts of meetings. From what I could tell, the point of that advisory board was to help the state work through some of the technical minutiae, much like the working groups created after the request for proposals was issued, by giving consumers a chance to raise questions and make comments about KanCare. The public engagements were either informational or an opportunity to raise questions on a conference call. Stakeholders could provide feedback on a range of issues from reimbursements, to cost savings, to value-added services, but there was never any discussion of how to implement proposed changes in terms of risk-based capitated managed care or fee-for-service or some combination of both.

According to the transcript of one of the Consumer and Provider Work Group meetings, the process by which stakeholder input flowed to actual decision makers went through two steps. First, officials took suggestions made during the work group and advisory group meetings to the KanCare Steering Committee. Second, the Committee then refers feedback to the Sub-Cabinet of the governor's office. "The KanCare Sub-cabinet is made up of Secretary Moser, Secretary Sullivan, Secretary Gilmore and the Lieutenant Governor so this is basically the Cabinet Secretaries reporting directly to the Governor on KanCare." However, there is no indication in the documents I analyzed of what specific information filtered back through to decisions makers. Thus, it is not possible to know if feedback actually influenced policy decisions, or if policy makers made decisions based on other input or criteria from the documents analyzed. For critics, the feedback was a critical component of their understanding of accountability.

### *Critics*

Accountability was important to critics, as well, but they talked about it in different terms. “Managed care can work, and can improve the provision of health services, however to make KanCare work for consumers, measures of accountability and transparency must be in place from the outset.”<sup>71</sup> KHCC felt that accountability and transparency on the part of policymakers were critical to any new Medicaid program. In fact, calls for accountability on the part of the state appeared as early as the summer 2011 public forums organized by the reform consultant. Indeed, one of the concerns listed in the first Member Involvement/Protection KanCare Workgroup in 2012 was “transparency of process, timelines and sufficient opportunity for feedback r/t care and needs for providers.”<sup>72</sup> I saw this sentiment repeated throughout the stakeholder feedback process in 2011 and 2012. When KHCC talked about accountability, they were directing their concern to the state – not consumers, unlike proponents. Specifically, accountability for critics meant information for consumers, independent public oversight, and proper expertise on health policy.

To ensure accountability and transparency, according to KHCC, there must be sufficient information for publics to hold the state accountable. This means independent non-state groups, such as advocates and researchers, should have access to timely data and analysis and “substantive consumer feedback,” according to KHCC. Data should include “access to care, quality of services, beneficiary satisfaction, health outcomes and cost expenditures,” and provider “network adequacy.” There must be “strategic pilot projects [and] ongoing policy and cost analysis.” This way, policymakers will have knowledge of what consumers need, and can build on that knowledge in how they design KanCare. KHCC effectively felt that KanCare should be well-informed by quality data from different sources to ensure consumers’ needs were

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<sup>71</sup> KHCC. “KanCare: A Review.”

<sup>72</sup> KANCARE Workgroup Member Involvement/Protections July 13, 2012, 10:00 am, meeting minutes.



being met. “Implementation must include substantive consumer feedback; a functioning consumer advisory group is crucial to inform all aspects of implementation and evaluation from day one.”<sup>73</sup> Information, both in the form of data available to stakeholders, and in the form of consumer voices in the policymaking process, are essential to accountability.

Critics also wanted accountability in terms of independent public oversight. There were two oversight issues of concern to critics: the KanCare Ombudsman and the legislative oversight committee. According to documents Kansas submitted to the federal government in 2012, “[t]he Ombudsman will advocate for the rights and proper treatment of KanCare consumers through direct involvement and mediation with consumers, State policy divisions, and KanCare plans.” The KanCare Ombudsman “assists beneficiaries to navigate and access covered health care services and supports. Help individuals understand the delivery system and resolve problems and concerns that may arise between the individual and a provider/payer.”<sup>74</sup> This office, which was for a while literally a ‘one-man-show,’ functions as the official line of defense for consumers and their rights. When someone has a problem with their KanCare health plan, they can summon the Ombudsman for assistance, or if they have a question that their MCO cannot seem to answer, they can call her for help. This office is not unique. Other states such as Texas and Florida have Medicaid Ombudsman offices. Over concern of biased interests, the federal government stated in its special terms and conditions document for the KanCare waiver that the “independent Ombudsman program must exist outside of the Kansas Department of Health and Environment.” So Kansas placed the ombudsman office in the Kansas Department for Aging and Disability Services, one of the state agencies responsible for KanCare.

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<sup>73</sup> KHCC. “KanCare Position Summary.”

<sup>74</sup> “Role of the Ombudsman.” (note: not Ombuds-“person”) [http://www.kancare.ks.gov/download/Role\\_of\\_the\\_Ombudsman.pdf](http://www.kancare.ks.gov/download/Role_of_the_Ombudsman.pdf).

As KHCC stated, “[i]n our opinion, the position that has been created is not an independent ombudsman. We feel very strongly that for KanCare to work consumers need someone who is independent of the Medicaid program to handle their complaints and to serve as an independent voice for them.” They questioned the independence of the KanCare ombudsman, arguing that he/she should not be under the purview of state rules and an instrument of the state to solve each consumer trouble one by one, but should be in a position to challenge those rules and act out of empathy for consumers and see to their needs. The Ombudsman is in a precarious position where she/he must balance bureaucratic constraints on the one hand and compassion for consumers on the other. Lack of autonomy is one reason ombudsmen cite for rating their effectiveness as policy monitors and advocates lower than their effectiveness performing other mandated activities. In fact, the KanCare Ombudsman originally assigned to the job in 2013 did not act as an advocate per se, at least according to some critics. “He is *not* an advocate. He doesn’t believe he should be, nor does his boss,” explained Holly, echoing similar concerns KHCC made as to the independence of the Ombudsman. Critics were skeptical that the Ombudsman office – not the person who occupied it – could be an effective voice for consumers.

Critics also repeatedly issued concerns over meaningful public oversight of KanCare through the legislature. “Legislative oversight of KanCare will be an important tool for achieving the goals of KanCare, and for ensuring transparency and accountability for consumers and all stakeholders invested in making KanCare successful.” Advocates wanted “the committee [...] to have real oversight of KanCare, not just in name only.” Such oversight was necessary “to ensure that KanCare achieves its intended cost savings without jeopardizing the quality of care or services for Kansans.” KHCC lobbied legislators to support the bill by Robert Bethell to create the legislative oversight committee.

The measure was the last to be considered by the House on Sunday night and required 63 votes for the House to concur. Despite many days of hard work by advocates, the bill only received 54 votes, but we were only 9 votes short. We heard broad support from the Legislature this session for oversight of KanCare, even though the two chambers ultimately could not reach agreement about the specific composition of the committee or how those committee members would be appointed. Given this support, we are optimistic that their differences will be worked out and that effective legislative oversight can be accomplished.<sup>75</sup>

After the bill passed the Senate unanimously, Representative Bethell died in a car accident.

According to all three legislators I met, the goals and the powers of the oversight committee were, in late 2013, inchoate and uncertain. Thus, it was a committee created to oversee a program, but what it was supposed to do to actually oversee KanCare and what it could do to hold MCOs responsible was up in the air. As Holly, who was a member of the Legislative Oversight Committee, stated, “I am unclear as to the role of the Committee.” Not only that, but the membership of the Committee was problematic from the point of view of critics.

To be accountable, critics expected relevant expertise among those who are responsible for overseeing KanCare. A body that is charged with making sure a program runs correctly should have some level of knowledge about the substance of that program, it would seem. Michelle, who was not a member of the Legislative Oversight Committee, explained that this was not the case in practice. When I spoke with her in 2013, she said that “there is no one with a health background” on the Committee. She had a professional background in health care and could offer a genuinely informed view on KanCare, but she was not granted the opportunity to be on the Committee. Michelle was troubled by the absence of relevant expertise. “It is sad for the people of the state,” she said. I asked her how the membership of the Committee was formed, and her response was the “a specific individual got to pick people for the committee.” Michelle

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<sup>75</sup> Carpenter, Tim. 2012. “State Rep. Bob Bethell dies in car crash.” *Topeka Capital-Journal*, May 21. Retrieved July 30, 2015 (<http://cjonline.com/news/2012-05-21/state-rep-bob-bethell-dies-car-crash>).

went so far as to request to be on the Committee the day it was announced but was denied. Interestingly, Nora, who did sit on the Legislative Oversight Committee, but who has no health care expertise, told me, “I don't even know how I got on the [Oversight] Committee. Someone asked if I would want to be on it, and I said sure!” Michelle did value the diversity of perspectives on the Committee. “We do need a variety of opinion.” Having diverse views on the committee was important to her, but there did need to be at least someone on the Committee who knew something about health policy or health care, she felt. Apparently, though, someone was paying attention to the lack of expertise. In 2014, KHCC noted in legislative testimony their appreciation of Kansas House Bill 2025, which required that members of the Legislative Oversight Committee be appointed from standing House and Senate Health Committees. This way, the Committee will have substantive expertise in health policy, which makes logical sense. This bill went into effect July, 2015.

The legislators who were critics of KanCare said that the political makeup of the committee was not balanced ideologically. Holly said the “balance of the committee is a problem. All five Republicans are conservative with no moderates. Three of them are hard Right. Four are Democrats, three of whom are moderates and one is hard Left.” The chair and vice-chair at the time were conservative Republicans. Thus, the process of creating the committee and its functions raises questions about the extent to which public oversight is effective or meaningful. Can a legislative committee that is aligned ideologically, in part, with the governor – KanCare’s main champion – be an objective observer? To what extent would such a committee actually hold the MCOs accountable? Would doing so be potentially in conflict with the governor? At least early on, the public accountability critics sought through legislative oversight and an ombudsperson was not to their satisfaction. For there to be effective public oversight,

though, critics felt that stakeholders should have a voice in the KanCare policymaking process. A study of Florida's managed care program in 2006 arrived at the same conclusion because of the potential conflicts between MCO and program goals and the vulnerability of certain Medicaid populations.<sup>76</sup> In other words, publics needed access to the mechanisms of oversight for it to be meaningful.

KHCC argued that reform should be “consumer focused,” which from its point of view meant consumer needs and voices should be central to the process of reform and the final product. Scholars agree (Hodin 2013; Miller and Rudder 2013). KHCC organized a panel in 2012 to discuss managed care in Kansas, at which one of the expert panelists contended that “advocates need to ensure their voices are heard,” and that “consumer advocates should stay engaged in the process throughout.”<sup>77</sup> From the outset, the state kept publics engaged in the Medicaid reform process through different workgroups and committees. KHCC and other advocates participated in these groups, according to meeting minutes. As far as public engagement after implementation was concerned, KHCC worried about situations that left consumer voices out of the picture. For example, the state created an advisory board after implementation in 2013, which was different from the one created in 2012, but there was one problem. No individual Medicaid beneficiaries were on the committee. As KHCC noted, “[w]e are concerned that the council, created to advise the Governor on KanCare implementation, will not include consumer members, which will limit its ability to address the health care needs of Medicaid consumers.” This group was essential to provide feedback to policymakers on how

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<sup>76</sup> McLean, Jim. 2013. “Study Calls for Monitoring of Medicaid Managed Care Companies.” *KHI News Service*. Retrieved November 7, 2013 (<http://www.khi.org/news/2013/oct/09/study-calls-monitoring-medicaid-managed-care-compa/>).

<sup>77</sup> “# KanCare and Consumer Rights: A Recap of KHCC’s Medicaid Summit” (<http://kshealthconsumer.com/?p=2868>).

KanCare worked in practice. The advisory board concept is important for democracy and keeps voices included in the political process (Grogan and Gusmano 2003). However, it is not uncommon for states to largely ignore consumer advocates (Miller and Rudder 2013). According to the Centers for Medicare and Medicaid in 2011, “[c]ollaboration with consumer and consumer advocacy groups is critical. In order to achieve the important goals of better health and better care with lowered costs, we must continue to put our beneficiaries first.” Furthermore,

“Medicare-Medicaid enrollees, their families and consumer organizations working with them also have a central role to play in helping to design a person-centered system of care. Therefore, CMS encourages and expects active and meaningful State engagement with stakeholders (Hodin 2013: 90).

Echoing the federal government in their 2013 testimony to the legislative oversight committee, KHCC said

We believe that consumers are the experts in their own health care. Consumers know when their health needs are not being met, and are well suited to address problems and offer solutions. As a result, it is crucial for Medicaid consumers and consumer advocates to be fully involved in KanCare decision making and implementation.

KHCC’s interpretation of “expert” extends beyond what policymakers deem as “expertise,” at least in light of the law requiring Legislative Oversight Committee members to come from Senate and House health policy committees. That is, KHCC challenges policymakers’ notion of what constitutes an “expert.”

In all, accountability meant *public* accountability, in the sense that the state should not only take responsibility for consumers but that consumers and the public should be more involved in the reform process and in KanCare after implementation. Critics were aware that consumers needed to be responsible. They took that for granted. “There was never a time when patients were not expected to be responsible,” Michelle argued. “There has always been a problem with patient follow through. Someone in the system has to make them responsible.”

Consumers may not always have the resources to comply with treatment regimens, or even be able to find reliable transportation to a doctor's visit. To be accountable, consumers needed to be empowered. It is about "being allowed to have those tools to be responsible." Critics stressed the constraints consumers face because of limited resources and poverty and the necessity for the state to help them overcome those obstacles. Health care is more than just "sickness care," Michelle explained, and must consider the "economic limitations" of poverty that inhibit personal responsibility. The goal of KanCare, she said, was "to improve health through wellness," which was no different in the previous system from her perspective. This is "very hard to do when fighting poverty." In that sense, Nora, too, was confused about the "rewards" and "incentives" of KanCare to encourage personal responsibility. "I don't understand how" that is supposed to work in practice, given barriers at the heart of the experience of poverty. Thus, it was not the actions of consumers that were necessarily of concern to critics as far as accountability goes. Critics were concerned that the state was not taking adequate measures to include consumers and the public in its decisions on how to reform Medicaid. Ultimately, critics felt that health care should be a shared responsibility of the state, the public, and consumers, a claim that challenged the devolution of health care in Kansas.

Underlying the competing claims of accountability was an implicit debate over the location of the responsibility for care in society. While Medicaid is still a public program, the extent to which the state is involved in the daily functioning of it is lower under KanCare. Enrolling all consumers in a private managed care plan means that the state took less of a role in the lives of Medicaid consumers as a whole. Proponents might disagree, because the state held a variety of public forums and sought public input into the reform process and design of KanCare, it is following the trend of what other states are doing to reform their Medicaid programs but

trying to do it better, and it is still financing Medicaid through public dollars. In contrast, critics said that the state should be more responsible by strengthening public accountability, though they did not necessarily disagree with further privatization as such. In response to this debate was the formation of the Legislative Oversight Committee and the Ombudsperson. Still, critics were neither convinced that the Ombudsperson was independent enough, nor were critics certain that the Oversight Committee had any real teeth. Going forward, policymakers acknowledged the input they received, and it is possible some aspects of the program changed based on that feedback, though documents do not make clear connections between feedback and concrete policy changes. As such, critics were still not convinced policymakers were listening. The incessant call for public accountability throughout the legitimization process was akin to a dog nipping at the heels of policymakers to remind them that publics expected to be involved and heard. In other words, there was an unreconciled conflict between where proponents and critics thought the location of the responsibility for care should be in society: in the hands of individuals and the market with government playing less of a role, or under the purview of public institutions with consumers expected to do no more than they always have. This debate continued to play out without resolution, and the conflict ensued with how each side saw KanCare's success.

## **Success**

### *Proponents*

The third theme to emerge is the success of KanCare. Proponents made numerous claims indicating success, according to documents from 2013 and 2014. Cost growth in Medicaid declined to 5.2 percent when it had been seven-percent for the previous decade, according to proponents.<sup>78</sup> For instance, emergency room utilization declined by 22 percent and primary care

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<sup>78</sup> "KanCare Advisor, March, 2014." ([http://www.kancare.ks.gov/download/FEB\\_24\\_2014\\_KanCare\\_Advisor.pdf](http://www.kancare.ks.gov/download/FEB_24_2014_KanCare_Advisor.pdf)).



utilization increased by 28 percent under KanCare in the first couple of years, according to proponents, which reduced costs. “We are starting to see more integration of care,”<sup>79</sup> which means that, according to Kansas Department of Disability and Aging Services testimony to the Legislative Oversight Committee in 2013, there is more coordination of medical, behavioral, and long-term support services under KanCare than under the old system. As a result, officials argued that the decrease in duplicate services is saving the state money, though it is unclear exactly how much. They also stated that out of the 2,000 people awaiting home-based care services who have physical disabilities, 100 individuals began receiving these services after June 30, 2013, a promising development for the cost savings KanCare was purported to bring. Proponents also made claims about the other two goals, improved health outcomes and quality of care.

Another success claim is improved health outcomes and quality of care. There are numerous examples from the documents I analyzed. The 2014 KanCare Annual Report stated that enrollments increased by four-percent in 2013 and continued to increase in 2014, implying that consumers were being served. Average claims denials between January and September 2013 (16.68%) were lower than in the same period in 2012 (20.74%) under arrangements with different MCOs.<sup>80</sup> An article published in *The Wichita Eagle*<sup>81</sup> by Shawn Sullivan and Robert Moser, Secretary of Kansas Department of Health and Environment, giving an update on the integration of consumers with intellectual and developmental disabilities into managed care declared that “in 2013 [...] more people received increases in services than experienced

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<sup>79</sup> KDADS testimony to Legislative Oversight Committee, October, 2013.

<sup>80</sup> KDHE testimony 2013.

<sup>81</sup> Sullivan, Shawn and Robert Moser. 2014. “Shawn Sullivan and Robert Moser: Integration of I/DD care going smoothly so far.” *The Wichita Eagle*, April 17. Retrieved September 20, 2015 (<http://www.kansas.com/opinion/opn-columns-blogs/article1140359.html>).

decreases.” They cited one anecdotal case, “Becky,” who “is living a more independent, individualized and happy life.” It was better care coordination she experienced that improved her situation, the article claimed. Another success story from mid-2013 exemplifies proponents’ success claims. A consumer with Huntington’s disease, psychiatric troubles, and a cancerous tumor was in jail for stealing food at a grocery store.

His Amerigroup Kansas care coordinator guided him through the eligibility process for waiver services and facilitated access to the long-term services and supports he needs. With the help of our team, we were able to get him out of jail and off the streets while ensuring he receives integrated care and support to help him live as independently as possible.<sup>82</sup>

Prevention-oriented services to encourage consumers to be more responsible with their care are now covered under KanCare. Secretary Sullivan cited the success of KanCare value-added services as evidenced by people receiving bariatric surgery, a life changing procedure that was not available to consumers before 2013.<sup>83</sup> In fact, \$6 million worth of these new services were provided in 2013, for example according to the March 2014 KanCare Advisor.<sup>84</sup> In this same issue, it states that “[b]ecause of the efficiencies in KanCare, more than 700 Kansans with physical and developmental disabilities now have access to services they had been waiting years to receive.” There is not an indication of what those services are, though. In all, KanCare was a success as proponents suggested, but critics had a different take on the outcomes of KanCare.

### *Critics*

Critics did see some successes, but just not the same ones claimed by the state. Advocates appreciated that persons with intellectual and developmental disabilities were not enrolled in managed care until 2014. They felt encouraged by independent legislative oversight and policies

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<sup>82</sup> “KanCare Advisor, May, 2013.” ([http://www.kancare.ks.gov/download/KanCareAdvisor\\_5\\_10\\_2013.pdf](http://www.kancare.ks.gov/download/KanCareAdvisor_5_10_2013.pdf)).

<sup>83</sup> I observed this at a meeting with School of Social Welfare graduate students and faculty in 2013 at The University of Kansas.

<sup>84</sup> “KanCare Advisor, March, 2014.” ([http://www.kancare.ks.gov/download/FEB\\_24\\_2014\\_KanCare\\_Advisor.pdf](http://www.kancare.ks.gov/download/FEB_24_2014_KanCare_Advisor.pdf)).

to ensure timely payments to providers. However, critics said that providers were still dealing with delays in authorizations for treatments, and that MCOs were denying claims that were approved under the old Medicaid system. When I met with Holly at her Senate office in Topeka, she showed me two stacks of papers about 18 inches high on her desk, which represented over \$600,000 in delayed care just in Topeka alone. She said that “prior authorization is a barrier to care,” and that the “payment and billing processes are bad.” She felt that MCOs “make money by delaying, not paying, or making it a big hassle.” What was even more troubling to me was that Holly told me there has been an “increase in claims with adult protective services,” which she attributed to some consumers’ hours of in-home care being cut. She also thought that some consumers receiving long-term supports were seeing a reduced number of hours of care, a point I will revisit in Chapter 5. In addition, MCO reimbursements to providers were slow. However, the state did address this problem after extensive attention given to it by advocates. “The State supported legislation, in collaboration with the Kansas Hospital Association, Kansas Medical Society and other provider groups, that calls for applying interest penalties on late payments from MCOs to providers.”<sup>85</sup> This is not to say that KHCC caused the state to respond to this issue, but simply that the response did come after consumer and provider advocates made repeated calls for attention to this problem. According to a KanCare performance summary provided as testimony to the legislative oversight committee in 2013, none of the MCOs, except one in one month, had achieved the performance measure of timely claims processing between January and June of 2013.<sup>86</sup> The KanCare Annual Reports of 2013 and 2014 revealed that the three MCOs all lost money both of those years. Data for 2015 are not yet available at the time of

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<sup>85</sup> “2014 KanCare Annual Report,” p. 16.

<sup>86</sup> Defined as “100% of clean claims are processed within 20 days, 99% of non-clean claims are processed within 45 days, and 100% of all claims are processed within 60 days.” A clean claim is one in which there are no errors.

this study. As for some of the value-added service, critics were not convinced of their efficacy for improving health outcomes. Holly felt it was “too early to tell” if adult dental care was making a difference. Nora said she thought the supposed competition between the three MCOs “would not make much difference to the consumer, but it is more challenging to providers. It is an added complexity to providers.” “Providers are paying the cost of increased complexity,” Nora thought. She was afraid KanCare was “rewarding people who limit health care.” Michelle’s fear was that KanCare was actually harming people, but she said that she “sees no evidence of this.” She cautioned that it is important to think critically about anecdotal evidence of problems, or success for that matter. It is what you “hear versus what you know.” I asked Michelle how the state measures success, and she responded, “it depends on who is defining success.” In all, some critics thought KanCare was going “smoothly,” at least in the beginning, while others saw continued problems, such as reimbursement delays and claims denials. It seems that from critics’ perspectives, the troubles with implementation were not isolated to consumers, but impacted providers as well. I will explore the implications of KanCare for consumers and providers in the following two chapters of the dissertation.

To conclude, the three themes common to proponents and critics – need for change, accountability, and success – were sources of contention. Each group saw these themes differently. I expected that each group might have competing perspectives, but it was the substance of those perspectives that I find instructive. Both agreed that change was needed, but did not agree on the nature of the change or the impetus behind it. Proponents emphasized success, while critics pointed out problems, which I anticipated. There is a broader political context, though, that proves instructive to consider in this devolution debate.

### **KanCare Politics in Perspective**

Kansas is often referred to as a 'red state,' indicative of its historically strong Republican leanings. The current governor, Sam Brownback, is from the conservative wing of the Republican Party, but the last two governors, Kathleen Sebelius and Mark Parkinson, were Democrats, an era during which the conversation over Medicaid reform began in Kansas. Despite Thomas Frank's infamous assertion that Kansas is a red state because people are duped into voting against their own interests, moderate politics is still a force in Kansas evidenced by civil society organizations such as the MainStream Coalition, a group of moderate Republicans, Democrats, and independents. There is, in fact, a long history of moderation and progressive politics in Kansas, which includes strong support for well-funded public education, a clear separation of church and state, and a rejection of extremism (Wuthnow 2014). As such, the political climate in Kansas is undecided and dynamic, as the closeness of the 2014 gubernatorial race between incumbent Brownback and Democrat Paul Davis might suggest. Yet, in the face of the state's contentious politics, social policies in Kansas show a definite turn to a more conservative bent predicated on neoliberal principles.

Over the last several years, policymakers in Kansas worked to reduce the size of government. As the former Budget Director of Kansas, Steve Anderson, stated in a 2014 presentation to a conservative group in Oklahoma,

The papers told us we had a \$500 M budget deficit . . . We cut spending immediately. The great thing about Kansas is it is a strong executive powers state. The Governor's cabinet secretaries run the government agencies. So when he turned me loose to twist arms, I was able to do that, and they cut spending. Brownback said to me, 'every cabinet secretary has complained about you. Keep doing what you are doing.'<sup>87</sup>

Spending cuts have a direct impact on the ability of the state to fund education, social programs and basic services, such as roads. Cuts in the form of more restrictions on TANF and SNAP

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<sup>87</sup> "The Miracle Financial Plan Kansas Uses - Steve Anderson - 03/12/2014." Retrieved May 25, 2016 (<https://www.youtube.com/watch?v=1NLh5v7RJso>).

recipients, for instance, places further strains on the poor. Not expanding Medicaid, as discussed earlier, does nothing to help weakening safety net resources, such as rural hospitals struggling to survive. Outsourcing administrative functions to the private sector for KanCare, such as the MCOs Amerigroup and United Health Care, moves money out of the pockets of Kansas workers to companies and employees outside the state who spend money and pay taxes in other states. Threats to the Kansas state employee retirement fund, such as through multiple delayed payments, may create precarious conditions for some families. Cuts to spending went hand-in-hand with cuts to income taxes for many individuals and businesses.

One of Kansas' signature policies in the last few years has been its tax policy. To put the state on a "glide path to zero" income tax<sup>88</sup>, the state of Kansas passed House Bill 2117 on May 22, 2012, which eliminated the top tax bracket from income tax, cut all income tax rates, and exempted more than 330,000 business owners from income tax rolls<sup>89</sup>. Much like the crisis discourse KanCare proponents used to drive Medicaid reform, as Steve Anderson again said, "the \$500 million deficit actually helped us . . . we can claim 'crisis,' which it was, and we can go in and twist arms." He said, "You have to frame the debate."<sup>90</sup> Therefore, the income tax cuts were a necessary solution to a crisis, or so the claim went. Proponents of the bill hailed it as a way to cut spending and grow the Kansas economy, while critics warned of a budget crisis. The revenue generated from the tax on small business accounts for about one-third of the state's budget. Meanwhile, the Governor's proposal to eliminate income taxes for about 388,000 people

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<sup>88</sup> Morris, Frank. 2013. "In Kansas, a Glide Path to No Income Taxes: Will It Work." *National Public Radio*. Retrieved July 1, 2015 (<http://www.npr.org/2013/02/15/171822472/in-kansas-a-glide-path-to-no-income-taxes-will-it-work>).

<sup>89</sup> Lowry, Bryan. 2015. "Kansas House, Senate pass tax increases, end 113-day session." *The Wichita Eagle*, June 12. Retrieved July 1, 2015 (<http://www.kansas.com/news/politics-government/article23827492.html>).

<sup>90</sup> "The Miracle Financial Plan Kansas Uses."

living in poverty, which was projected to cost the state only \$19 million annually<sup>91</sup>, never made it to the House. What the House also rejected were cuts to credits and deductions, such as to mortgage interest, child and dependent care, and the earned income tax credit. Sales tax also increased, a change felt more by lower and middle-income individuals who spend a higher proportion of their incomes on consumption than higher income individuals do. By 2015, Kansas had roughly a \$400 billion budget deficit. In effect, poor and lower income working Kansans are disproportionately subsidizing the effort to make Kansas a no state income tax state.

The idea is that tax cuts will generate economic growth in Kansas, which will help people by creating jobs, etc. “You cannot generate economic activity by moving money from one person to another. You need to let the free market work,” former Kansas Budget Director Steve Anderson said in 2014.<sup>92</sup> News reports have claimed the cuts drove job growth, higher employment rates, migration to Kansas from Missouri, and increased state revenues – all “good news” for Kansas.<sup>93</sup> As such, Kansans were “reaping the benefits” of the 2012 tax cuts.<sup>94</sup> The tax cuts were to bring “enormous prosperity,” stated Arthur Laffer.<sup>95</sup> Many other reports disagree<sup>96</sup>,

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<sup>91</sup> Shorman, Jonathan. 2015. “Kansas Chamber asks lawmakers supporting tax hikes to make changes in 2016.” *The Topeka-Capital Journal*, June 9. Retrieved July 1, 2015 (<http://cjonline.com/news/2015-06-09/kansas-chamber-asks-lawmakers-supporting-tax-hikes-make-changes-2016#gsc.tab=0>).

<sup>92</sup> “The Miracle Financial Plan Kansas Uses.”

<sup>93</sup> Sinquefield, Rex. 2015. “\$486 Million In Growth Later, Kansas' Historic Tax Cut Should Set Example for Neighbors.” *Forbes*, October 21. Retrieved June 6, 2016 (<http://www.forbes.com/sites/rexsinquefield/2015/10/21/486-million-in-growth-later-kansas-historic-tax-cut-should-set-example-for-neighbors/#75dea8142a94>).

<sup>94</sup> Wilson, Andrew. 2015. “Seeded With Tax Cuts, Kansas Harvests the Benefits.” *The Wall Street Journal*, May 15. Retrieved June 6, 2016 (<http://www.wsj.com/articles/seeded-with-tax-cuts-kansas-harvests-the-benefits-1431729743>).

<sup>95</sup> Wistrom, Brent D. 2012. “Economist Arthur Laffer says tax cuts will help Kansas grow.” *The Wichita Eagle*, August 14. Retrieved June 6, 2016 (<http://www.kansas.com/news/article1097282.html>).

<sup>96</sup> Leachman, Michael and Mai. 2014. “Lessons for Other States from Kansas' Massive Tax Cuts.” Center on Budget and Policy Priorities. Retrieved June 7, 2016. (<http://www.cbpp.org/research/lessons-for-other-states-from-kansas-massive-tax-cuts>).

Vockrodt, Steve. 2015. “Brookings Institution: Kansas income tax cuts were not a good idea.” *The Pitch*, July 28. Retrieved June 7, 2016 (<http://www.pitch.com/news/article/20562140/brookings-institution-kansas-income-tax-cuts-were-not-a-good-idea>).

especially when ordinary Kansans talk about the state of affairs in Kansas.<sup>97</sup> Many people are not hearing the “good news” and are not seeing the “enormous prosperity.” The fact is that the “trickle-down” theory does not hold up to empirical scrutiny (Treas 1983; Lobao and Hooks 2003; Reed and Rogers 2004; Kenworthy 2009). Even the dearth of research that finds support indicates that positive effects of corporate income tax cuts on job creation occur only within the first year of the cuts (Shuai and Chmura 2013). Overall, trickle-down is more rhetoric than scientific fact.

Nevertheless, policymakers propagate the trickle-down theory in public discourse despite the lack of evidence, or even contrary to evidence otherwise, and implement policy predicated on it. The fact that other states, like Louisiana, cut their income taxes likely inspired the Kansas ‘glide path to zero,’ but it is also an idea that some hold as conventional wisdom within certain circles. The common sense is that government should be “smaller,” and as such, will be more efficient and produce better outcomes. This is akin to what Billy, the public information official, said about “doing more” in Medicaid “with less.” Tax cuts then mean cuts to spending, and this is what some Kansas lawmakers hoped would happen,<sup>98</sup> or what a *National Review* columnist criticizing the Kansas tax cuts called “Starve the Beast.”<sup>99</sup> The relevance of the tax cuts in 2012 is that they signal a larger neoliberal turn in Kansas policy influenced by a certain flavor of conservative and right wing groups. There are organizations that develop policy ideas that Kansas, along with other states, then adopt. I will discuss three such organizations whose ideas

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<sup>97</sup> Carpenter, Tim. 2016. “Tour Reveals Kansans' Frustration with Politics of Budget, Education And Taxes.” *Topeka Capital Journal*, April 26. Retrieved June 6, 2016 (<http://cjonline.com/news/state/2016-04-26/tour-reveals-kansans-frustration-politics-budget-education-and-taxes>).

<sup>98</sup> Shields, Mike and Phil Cauthon. 2012. “Governor signs tax cuts into law.” *KHI News Service*. Retrieved June 7, 2016 (<http://www.khi.org/news/article/governor-signs-tax-cuts-law/>).

<sup>99</sup> Williamson, Kevin D. 2016. “Starving the Beast in Kansas.” *National Review*. Retrieved June 7, 2016 (<http://www.nationalreview.com/article/434885/kansas-tax-cuts-wont-starve-government-beast>).



inform the neoliberal ethos evidenced in current Kansas policy: American Legislative Exchange Council, Kansas Policy Institute, and Foundation for Government Accountability.

The non-partisan American Legislative Exchange Council (ALEC) is an organization comprised of about 25 percent of state legislators and stakeholders from numerous policy areas that supports limited government, free markets, and federalism.<sup>100</sup> All ALEC members in Kansas are Republican.<sup>101</sup> It advertises on its website a “model policy library” available to policymakers, policies intended to “reduce the cost of everyday life and ensure economic freedom.” These are laws written generically with blanks in which policymakers insert the names of their own states and adjust the language to fit their states’ needs. The policies reflect the interests of corporations, such as ALEC member and sponsor Kansas-based Koch Industries and its owners, Charles and David Koch.<sup>102</sup> Legislators attend ALEC meetings to share ideas but also to take ideas learned back to their home states to implement. A variety of ALEC-inspired bills appeared in the Kansas Legislature in 2013, such as the HB 2553 Health Care Compact Act, which is the same wording of a document in ALEC’s policy library.<sup>103</sup> Under this policy, states can form partnerships to allow competition between health insurers across state borders so that consumers can choose health plans from partner states. That is, states can bypass federal regulation of Medicaid and Medicare,<sup>104</sup> which reflects the initial sentiment of Medicaid reform in 2011 in seeking a block grant. More relevant to KanCare is a policy in ALEC’s model policy library the wording of which is familiar: “Resolution on Improving Quality and Lowering Costs for States through

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<sup>100</sup> “About.” Retrieved October 25, 2016 (<https://www.alec.org/about/>).

<sup>101</sup> “Kansas ALEC Politicians.” Retrieved October 25, 2016 ([http://www.sourcewatch.org/index.php/Kansas\\_ALEC\\_Politicians](http://www.sourcewatch.org/index.php/Kansas_ALEC_Politicians)).

<sup>102</sup> Graves, Lisa. 2011. “ALEC Exposed: The Koch Connection.” *The Nation*, July 12. Retrieved June 9, 2016 (<http://www.thenation.com/article/alec-exposed-koch-connection/>).

<sup>103</sup> Model Policy: Health Freedom Act.” Retrieved October 25, 2016 (<https://www.alec.org/model-policy/health-freedom-compact-act/>).

<sup>104</sup> Ranney, Dave. 2014. “Health compact bill resurfaces in Kansas House committee.” *KHI News Service*. Retrieved June 9, 2016 (<http://www.khi.org/news/article/health-compact-bill-resurfaces-kansas-house-commit>).

Medicaid and Managed Care” dated September 2010. According to ALEC, “[t]his resolution encourages the implementation of coordinated, risk-based, capitated programs to control costs and improve quality of care for all Medicaid beneficiaries, including those requiring long-term care services.” In mid-2011, along with many Kansas legislators, the Medicaid Director attended an ALEC conference and attended health care-related panels.<sup>105</sup> The following February witnessed a protest in Topeka in opposition to policy changes, including Medicaid reform, attendees felt ALEC influenced.<sup>106</sup>

Another organization that makes its voice heard in Kansas politics is the think tank Kansas Policy Institute (KPI). Its motto is “advocating for free market solutions to public policy issues and the protection of personal freedom for all Kansans,”<sup>107</sup> While there is no evidence KPI influenced KanCare directly, its ideas do inform the broader policy environment within which KanCare emerged. KPI disseminates policy advice to lawmakers through legislative testimony and promulgates its laissez-faire ideas through opinion pieces in newspapers and events around the state of Kansas. KPI models itself after the CATO Institute to accomplish what that organization does nationally but at the state level.<sup>108</sup> It acts as a mechanism for realizing interests of business and policy elites under the guise of “research.” For instance, KPI connects to ALEC through its president and the research staff and to Koch Industries through its Board of Directors. KPI has government connections through a former Budget Director who was a consultant for KPI after leaving his government job in 2013, and who had worked for Americans for

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<sup>105</sup> Cauthon, Phil. 2011. “A legislator’s guide to repealing Obamacare: Are Kansas officials studying the ALEC playbook?” *KHI News Service*. Retrieved June 9, 2016 (<http://www.khi.org/news/article/elements-kansas-policy-mirror-guide-repealing0>).

<sup>106</sup> McLean, Jim. 2012. “Hundreds protest Brownback initiatives, influence of ALEC.” *KHI News Service*. Retrieved June 9, 2016 (<http://www.khi.org/news/article/rally-staged-protest-brownback-policies>).

<sup>107</sup> “History and Mission.” Kansas Policy Institute. Retrieved June 30, 2016 (<https://kansaspolicy.org/history-mission/>).

<sup>108</sup> Ibid.

Prosperity, a Koch-supported organization that promotes tax cuts and deregulation, before entering public service under Brownback.<sup>109</sup> It also has ties to real estate and building industries through its Advisory Board. At the heart of its tax policy proposals is economist Arthur Laffer<sup>110</sup>.

Laffer's consulting firm, Arduin, Laffer, and Moore, received \$75,000 in 2012 for advising the Kansas Governor on his decision to cut taxes. Laffer testified before the Kansas legislature in January 2012 presenting his "Rich States, Poor States: ALEC-Laffer State Economic Competitiveness Index"<sup>111</sup> to assert his tax theory. Two months prior, he presented a report on tax policy to the Oklahoma Council for Public Affairs, a conservative think tank connected to KPI through the State Policy Network.<sup>112</sup> His report, as well as the "Rich States, Poor States" document for which Sam Brownback wrote its original introduction,<sup>113</sup> argues that income tax cuts generate economic growth. These reports supported Oklahoma and Kansas' decisions to cut income taxes. Soon after, researchers questioned Laffer's method and found conflicting results, suggesting that the reverse was actually true: tax cuts hurt the economy.<sup>114</sup> Laffer's firm has advised other states in a similar way on tax policy. For instance, Laffer was a consultant for Gov. Rick Scott in Florida, and one of the firm's partners, Donna Arduin, was the

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<sup>109</sup> Rothschild, Scott. 2013. "Brownback's former budget director, Anderson, will work on state fiscal policy with KPI." *Lawrence Journal World*, September 6. Retrieved June 29, 2016 (<http://www2.ljworld.com/news/2013/sep/06/brownbacks-former-budget-director-anderson-will-co/>).

<sup>110</sup> In the Acknowledgements of Laffer's "Rich States, Poor States" booklet published by ALEC, Dave Trabert president of KPI is thanked as a contributor.

<sup>111</sup> American Legislative Exchange Council. Retrieved June 30, 2016 ([https://www.alec.org/app/uploads/2015/10/RSPS\\_8th\\_Edition-Final.pdf](https://www.alec.org/app/uploads/2015/10/RSPS_8th_Edition-Final.pdf)).

<sup>112</sup> Its strategy: "State Policy Network works with our think tank affiliates to cultivate thriving free-market movements in every state that are deeply rooted in and committed to economic and political freedom." Retrieved June 30, 2016 (<https://spn.org/directory/>; <https://spn.org/about/>).

<sup>113</sup> "The brain behind the Brownback tax cuts Economist Arthur Laffer remains a lightning rod." *KHI News Service*. Retrieved June 29, 2016 (<http://www.khi.org/news/article/brain-behind-brownback-tax-cuts/>).

<sup>114</sup> "Arthur Laffer Regression Analysis is Fundamentally Flawed, Offers No Support for Economic Growth Claims." Institute on Taxation and Economic Policy. Retrieved June 30, 2016(<http://www.itep.org/pdf/LafferRegression.pdf>).

budget director in several states including Florida under Jeb Bush.<sup>115</sup> The Florida connection to KPI vis-à-vis Laffer's firm is interesting, given the evidence of another right wing think tank's influence on Kansas health policy.

Also connected to KPI through Laffer, and the State Policy Network, is the Florida-based Foundation for Government Accountability whose ideas have found their way into Kansas health policy. Instead of expanding Medicaid to cover low-income and the poor, one solution to health care access problems this think tank proposes, and that Kansas has adopted, is telling providers to spend their free time doing pro bono work instead of reimbursing them. While under a similar program in Florida, doctors have given “470,000 free visits, with the value of donated goods and services totaling nearly \$298 million,” does the care provided actually have a meaningful impact on health? Is it preventing emergency room visits? How accessible is the care? Also, Florida is not as rural of a state as Kansas is. Is there sufficient provider resources in Western Kansas or in the poorer urban counties to meet needs? These questions have no discernible answers. The rhetoric of work transfer from paid labor to unpaid donations of time and skill may sound good economically and politically to some, but to the people who actually need care, the benefit is uncertain. In addition, Kansas adopted another policy solution that is centered on consumer choice in health care. Consumers can save money by comparison shopping. They can choose doctors in or out of their insurance companies' networks, which the group calls “expanding access,” but is not about increasing provider resources in underserved areas. They claim that nearly 90 percent of consumers shop around, and so they are being given incentive to do what they already do under this plan. This seems a bit out of place. Could a more fruitful effort be incentivizing more providers, especially in oral health, to accept Medicaid? The “Volunteer

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<sup>115</sup> “Partners: Donna Arduin.” Retrieved October 25, 2016 (<http://www.arduinlaffermoore.com/partners/donna-arduin/>).

Care” and the “Right to Shop” programs are cases of where a right-wing think tank outside Kansas is writing legislation for Kansas. Meanwhile, consumer advocates, who actually work on behalf of Kansas citizens, struggle against a shifting of accountability from the public to the private. In fact, policies from this organization, including fighting Medicaid expansion, workfare, foster care, and cuts to nutrition assistance. Every solution this think tank promotes, Kansas has adopted. The common thread of each is either “charity” or “volunteer” based. Interestingly, the section on their website for health policy solutions with the subheading “Research” is blank, but the same page has links to several articles hailing the adoption of their solutions by a few states.

In sum, think tanks like KPI and the Foundation for Government Accountability, organizations for elites like ALEC and the National Governor’s Association, and consulting firms like Arduin, Laffer, and Moore provide a network through which specific kinds of knowledge – neoliberalism and conservative economic and social views – disseminate to state policymakers and inform policy. These are not the only avenues through which policy ideas circulate. State Medicaid directors, for instance, connect through organizations like the National Organization of Medicaid Directors, National Association for Developmental Disabilities, Behavioral Health Directors Association, National Association of States United for Aging and Disabilities and its Managed Long Term Services and Supports symposiums and Home and Community Based Services conferences, AARP, and Deloitte. Deloitte Consulting, which emerged in the document analysis, sells its services in the private and public sectors. Health and human services is one of its five public sector focus areas. One consulting firm ranked Deloitte “the leader in U.S. state and local government consulting” finding that

Deloitte is substantially immersed in the state and local government market, giving it a thorough understanding of clients' needs through previous experiences in the same state, or taking best practices from consulting services applied in other states.<sup>116</sup>

The fact that this organization sees government as a “market” is instructive, but that it is “immersed” in this market is much to the point. It is through these various sorts of organizations and groups that ideas informing Kansas policy, whether it is taxes or health care, diffuse across states over time. To see KanCare simply as a product of Kansas politics alone is to downplay the significance of the larger environment in which Kansas policymakers receive their ideas, or have their ideas shaped and legitimized. In turn, it is within this environment that local grassroots health care consumer advocacy organizations, like KHCC, must contend with well-supported organizations well situated in national networks of policy elites that, arguably, favor market-based solutions and welfare state retrenchment over advancing public institutions. Nevertheless, this organization, perhaps in a small way, shaped the discourse on KanCare through its legitimization process, suggesting that advocacy organizations, which may sometimes have few resources, can shift power relations between policymakers and publics.

## **Conclusion**

This chapter explored the contentious politics of Kansas Medicaid reform by comparing competing discourses of proponents of KanCare to those of its critics. Proponents were Kansas state agencies and policymakers, including a public information officer and a conservative Republican legislator, and critics were a health care consumer advocacy organizations, Kansas Health Consumer Coalition, and Kansas legislators – a moderate Republican, moderate Democrat and a liberal Democrat – critical of KanCare. Three themes emerged from document

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<sup>116</sup> “Deloitte named the leader in US state and local government consulting by Kennedy.” Retrieved June 30, 2016 (<http://www2.deloitte.com/us/en/pages/about-deloitte/articles/press-releases/kennedy-research-deloitte-leader-in-us-state-local-government-consulting.html>).

analysis and interviews with policymakers: a need for change, accountability, and success. Proponents and critics interpreted each of these themes in conflicting ways. First, proponents framed the need for change in terms of a crisis discourse, calling for immediate radical change to deal with a budget crisis, while critics were skeptical of such claims and how the state proposed to address them. Critics did not see a budgetary crisis, nor did they see the value in forcing persons with developmental and intellectual disabilities into managed care. There were conflicting views on the use of managed care in general. Second, proponents emphasized personal responsibility on the part of consumers and more accountability for MCOs, while critics called for the state to be more accountable and transparent. Third, each side had a different view of KanCare's success. Proponents made various claims of success within the first year of its implementation noting some areas for improvement, while critics raised concerns about ongoing problems and framed KanCare's success as questionable at best. Although critics challenged KanCare's legitimacy and the legitimacy of proponents' claims, they were willing to work with the state to shape KanCare into a program that was beneficial to consumers.

The extent to which KHCC, in particular, ultimately shaped KanCare is not entirely clear, though the final policy that went into effect in 2013 reflected some of the concerns they and other advocates expressed, including a Legislative Oversight Committee, an Ombudsman, pushing out inclusion of consumers with certain disabilities in managed care until 2014, and stronger regulations to ensure timely provider reimbursements. These outcomes may have implications for consumers and health care providers in the years to come. Meanwhile, the political context within which KanCare emerged and continues to evolve revealed that the discourse between KanCare proponents and critics was informed by a broader policy discourse of privatization and health care devolution among policy elites and conservative interest groups.

How much those outside forces actually shaped KanCare is uncertain, but the common ideas and networks suggest that KanCare is predicated on a conventional wisdom shared by Kansas policymakers and policy elites elsewhere and communicated through various policy channels.

When I first learned of KanCare in 2012, I wondered if it would actually pass given some of the criticism I was reading about it in the media. Some people were skeptical. Others thought it would be a total failure. Some said it would improve Medicaid, help consumers, and cut costs. While I would likely not be able to know the health outcomes of the reform beyond anecdotal cases, I wanted to make sense of why this reform, a policy solution that has such mixed empirical support and strong criticism from advocates and providers, was enacted. I needed to know why the reform happened to begin with, who was involved in developing its design, and what the process was by which KanCare developed from an idea to a concrete program. The sociological literature explains that interest groups have shaped the evolution of social policy in the U.S. The challenge for me was to look beyond bureaucratic and administrative processes of policymaking to explore the dynamics of how competing interests informed KanCare at the level of political discourse. As I see it, the influence of organized interest groups is complex. Nevertheless, the relative disagreements that emerged in the early days of KanCare over the economic situation of the state, the location of the responsibility of care, models of organizing Medicaid, and the capacity of KanCare to improve the lives of consumers set the stage for how consumers and health care providers would experience Medicaid in the future. In the next chapter, I explore what a few select consumers knew about the changes that came about in 2013. The state made efforts to get the word out about KanCare as part of the legitimation process, but as I will show, the message did not get through. What consumers did know suggests that the consumer choice model undergirding KanCare is problematic. The implications of this disparity



become evident in Chapter 5 where interviews with consumers and providers raise questions about the devolution of Kansas Medicaid, specifically work transfer to consumers and providers.

## CHAPTER 4

### Getting the Word Out

#### **Introduction**

In the previous chapter, I explored the legitimization process of KanCare through an analysis of the discourse between state proponents of reform and its critics along the issues of need for reform, accountability, and success. The purpose of this chapter is to continue exploring the legitimization process by comparing the state's KanCare public information campaign in 2012 and 2013 to what consumers actually knew about KanCare after implementation of the reform. I talked to seven KanCare consumers about KanCare, their thoughts on it, how they knew about it, and what health care choices they made and why. They were not the typical Medicaid beneficiary, as they all had college degrees. As such, I expected these consumers to know about KanCare, the changes that had been made, the benefits of the reform, and to explain how the new program was affecting them. While a couple of consumers expressed specific concerns about the new program and were aware of some of the changes, most consumers were confused, overwhelmed, or just did not know much about KanCare at all, despite the efforts by the state to get the word out. Information is key. The consumer choice model upon which KanCare is based is predicated on the availability of sufficient information and consumers making rational health decisions based on that information, but when there are variations and disparities in consumer knowledge in relation to what policymakers think consumers are supposed to know, the

devolution of responsibility shows its limitation. That is, the state expects consumers to know and do more at the same time consumers struggle to parse through and struggle with the information they have. I will begin the chapter by describing the KanCare public information campaign, and then I will discuss what KanCare consumers actually knew about KanCare.

### **KanCare: Getting the Word Out**

The state of Kansas used different strategies to inform Medicaid consumers, providers, and the general public about KanCare. For instance, the Kansas Department of Disability Services and Kansas Department of Health and Environment issued public service announcements beginning on the radio and television in late 2012, with ads both in English and Spanish.

[. . .] KanCare is a great new program! It will ensure that you still get the medical care you need. It will also help the state keep Medicaid costs down. You'll automatically be enrolled in one of three KanCare health plans [. . .] Each plan is offering its own special benefits. You will be able to change to a different plan if you'd like [. . .] The health plans will make sure you receive the services and screenings you need to stay healthy. The plans will help you better manage your chronic conditions. The goal is to help you stay out of the hospital as much as possible [. . .]<sup>117</sup>

From these announcements, people could learn about the change, the function of the program, that they would have a choice, and where to go to get more information. There was a billboard along Interstate 70 in eastern Kansas announcing KanCare, and there was a flyer titled “More Choices. Better Access. Healthy Patients” with “7 exciting features” that are “pro patient” and “savings by the numbers” that are “pro taxpayer.” The flyer states that “KanCare consumers can choose a plan that offers rewards for making healthy decisions to get vaccinations, have well

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<sup>117</sup> Moser. KanCare Commercial Scripts – October 2012. One minute public service announcement. Retrieved March 20, 2016 ([http://www.kancare.ks.gov/download/KanCare\\_Enrollment\\_Packets\\_PSA\\_Script\\_Moser.pdf](http://www.kancare.ks.gov/download/KanCare_Enrollment_Packets_PSA_Script_Moser.pdf)).

care visits and checkups, and follow the doctor's orders. Be healthy, get rewards—it's that simple."<sup>118</sup>

The state created the KanCare website ([www.kancare.ks.gov](http://www.kancare.ks.gov)) in September 2012 with specific pages each for consumers and for providers. Both sections had their own frequently asked questions site so that consumers and providers could see the information that pertained specifically to them. Consumers could read about benefits and services, enroll in a KanCare plan, see a calendar of events, and contact the KanCare Ombudsman. Providers could find information they need to be a KanCare provider, about billing issues, and an events schedule.

As part of their public outreach required by the federal government, state health agencies also held a series of public meetings across the state for consumers and providers. The meetings implied that if consumers have information about the changes to Medicaid and about the three health plans, they can make informed decisions about their health care. Similarly, if providers have sufficient information, they should be able to make the necessary adjustments to their daily operations to ensure their patients receive the care they need. From the vantage point of the consumer, the only change they should notice is that they have a different health plan and a new Medicaid ID card to present when paying for a doctor's visit and such. No change was one of the selling points of KanCare.

These mechanisms for consumer and provider information do not ensure everyone who needs information can get it. What about the consumers that did not attend the meetings because of a disability, or read the website due to no internet access, or even look at materials they might have received in the mail? The state did provide opportunities for consumers to ask questions at the public events, but over half of the 200 people in the audience left after the formal

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<sup>118</sup> [http://www.kancare.ks.gov/download/KanCare\\_ProPatient\\_ProTaxpayer.pdf](http://www.kancare.ks.gov/download/KanCare_ProPatient_ProTaxpayer.pdf).

presentation during the first meeting I attended, leaving far fewer people for the question and answer session. Many of the questions asked by consumers were questions that could be answered just by reading the KanCare website or were issues that were addressed earlier in the presentation. Questions tended to be about an individual's specific problem, not about KanCare in general or about its goals. If the experts could not answer their questions at that time, they asked for the person's contact information and offered to follow up with them at a later time, or asked them to speak after the meeting was over. Needless to say, one can only assume the individuals who left half way through the event had sufficient information, but there is no way to know.

The two meetings in Olathe and Lawrence were formal and offered little opportunity for sustained engagement, but the third event I attended for consumers, also in Lawrence, was markedly different than the other two. It entailed individualized consultations with officials from state agencies, the KanCare Ombudsman, and an MCO representative in which consumers could express their concerns about their new KanCare plans, ask questions, or seek resolutions to problems they experience. I sat there for an hour and saw only three consumers, one of whom was an older man who identified himself as having a disability. He talked at length to the KanCare Ombudsman, who was friendly and listened intently, about transportation problems he encounters. He said that he likes to walk around The University of Kansas campus for his health, but because that sort of activity does not count as a doctor's visit, he has difficulty securing a transportation service to take him there. This event emphasized specific individual personal troubles, not the overall program, though I was intrigued to see the team effort to resolve individuals' problems. Yet, it made me think: how many individuals are not receiving this level

of personal attention and having to go it alone? How many consumers could benefit from such personal attention?

My initial reaction was that this event was little more than a public relations stunt, but after more careful consideration, I had to think a bit differently. I thought about how attentive they were to the man with the transportation needs, when the Ombudsman was sitting forward, with his elbows on his knees actively listening, eyes focused on the man, or to a woman in the room who I could not hear but could see the body language of the MCO representative that suggested to me a seriousness about helping the person. Perhaps the officials present were genuinely interest in helping people. I think from observing the event from the inside out, actually being there, kept some of my cynicism at bay. The MCO representative was smiling, reassuring the woman that he would resolve her issue right there, and her reaction of a brief joyful laugh and a smiling ‘thank you’ suggested to me that I needed to think more critically about how KanCare is structured and the rhetoric of policymakers in relation to how people do KanCare on the ground.

Lastly, before the state automatically enrolled existing Medicaid consumers into one of the three available plans, consumers received letters in the mail in 2012 advising them of the upcoming change, and then received another mailing with information about their new plan in December, including their new KanCare insurance card. Beginning in January, consumers were told they had 90 days to select a new plan if they wanted.

Given the various strategies the state used to inform consumers about KanCare, I asked consumers what they actually knew about it and how. What they knew, or did not know, proved instructive. Consumers tended to know little about KanCare. Those few who were more politically active understood substantive details of KanCare better than others, while those that

knew little about it explained the ways in which they felt either overwhelmed or powerless in light of the information available. Their knowledge not only speaks to the relative ineffectiveness of the means by which the state communicated information to consumers. Consumers' stories speak to the labyrinthine nature of Medicaid, and how, without actively seeking information and being involved publicly, consumers can feel embedded in a system that makes little sense to them thus impeding their capacities to make fully informed decisions for their care, given the information available, resulting in acquiescence or cynicism. In the following section, I discuss what the consumers I interviewed knew. I divide the section into the three themes on knowledge that emerged from the data: knowledge of KanCare itself, knowledge of their choices as consumers, and knowledge of changes under KanCare. First, I turn to a description of who Medicaid consumers are nationally and in Kansas, followed by a brief summary of the consumers I interviewed for the study.

### **Medicaid Consumers: Who are They?**

#### *Consumers Nationally*

In 2013, the average monthly enrollment in Medicaid nationally was 57.4 million, 13.7 million of whom were adults, about 34 million children, and 9.6 million persons with blindness or disabilities<sup>119</sup>. Thirty-nine percent of Medicaid consumers were 21-64 years old in 2011, over 58 percent were women, and 40 percent were White, 22 percent Black, and 25 percent Hispanic. According to this same report, 22 percent of all Americans were enrolled in Medicaid at some point in 2010. Two-thirds of consumers are low-income pregnant women and children, while the other third is comprised of persons with disabilities and frail elderly. The latter two groups make

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<sup>119</sup> Centers for Medicaid and Medicare Services. "2014 Centers for Medicare & Medicaid Services Statistics Reference Booklet." Retrieved September 29, 2015 ([https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/CMS-Statistics-Reference-Booklet/Downloads/CMS\\_Stats\\_2014\\_final.pdf#tablei17](https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/CMS-Statistics-Reference-Booklet/Downloads/CMS_Stats_2014_final.pdf#tablei17)).

up two-thirds of Medicaid costs. Medicaid participation is not just limited to people living below the Federal poverty line, but include people living near poverty, thus making Medicaid a program for poor and low-income Americans. Education, another indicator of socioeconomic status, is important to consider for understanding who Medicaid consumers are.

Of individuals who received health coverage through Medicaid, 36 percent had less than a high school diploma, 45 percent had a high school diploma, 18 percent had a bachelor's degree and none surveyed had a master's degree<sup>120</sup>. In comparison, individuals who received health insurance through an employer were more likely to have a bachelor's degree (39%) or a master's degree (20%). The difference in education is significant, because less education correlates with less knowledge about Medicaid rules and perceptions of greater enrollment barriers (Stuber and Bradley 2005: 295), factors that could discourage people from enrolling in Medicaid who may need it, cause consumers to make mistakes that lead to loss of eligibility, or result in consumers making poor decisions about their health.

### *Consumers in Kansas*

In Kansas, 384,176 people were enrolled in KanCare by December 2013.<sup>121</sup> By the end of 2015, enrollment was 402,055, a little more than a six-percent increase from 2013.<sup>122</sup> The change in enrollment does not compare well to the national average, because Kansas has not expanded Medicaid like many other states. However, neighboring states that have not expanded Medicaid varied. Missouri saw a 12 percent increase in the same time period, while Oklahoma and Nebraska saw declines of one percent and five percent, respectively. Similar to national

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<sup>120</sup> Source: General Social Survey Cumulative Data File 1972-2012, R's highest degree (DEGREE) by source of health insurance (HLTHTYPE) (N=92).

<sup>121</sup> A few consumers on the ID/DD waiver may not have yet been enrolled in managed care at this time but may have still been on the old fee-for-service system. Retrieved September 29, 2015 ([http://www.kancare.ks.gov/download/KanCare\\_Annual\\_Report\\_to\\_CMS\\_DY\\_ending\\_12\\_31\\_13\\_FINAL.pdf](http://www.kancare.ks.gov/download/KanCare_Annual_Report_to_CMS_DY_ending_12_31_13_FINAL.pdf)).

<sup>122</sup> "Monthly Medicaid and CHIP Enrollment Data." Retrieved April 13, 2016 (<https://www.medicaid.gov/medicaid-chip-program-information/by-state/kansas.html>).

rates, women are a slight majority of Medicaid beneficiaries in Kansas (56%). Comparable data on race for Kansas was not available. The eligibility level for pregnant women and infants is 166 percent of the Federal poverty line, and for other adults, the level is 38-percent of the federal poverty line, or \$9,063 per year for a family of four, and 33 percent for parents receiving benefits under Temporary Assistance to Needy Families. Eligibility for children at different ages range from 133 to 245 percent of the federal poverty line. Non-disabled adults with no children do not qualify for Medicaid in Kansas, as is the case in several other states.

For this study, I interviewed seven KanCare consumers, four men and three women. As stated earlier, they differ from profiles of typical Medicaid beneficiaries. Six were White and one was African-American. Five had a disability, they all received Social Security Disability Income assistance, and one received Medicare benefits. Consumers ranged in ages from their mid-30's to mid-60's, and they all had at least a bachelor's degree. Most of them have been in the Medicaid program in Kansas for many years. Appendix F includes three tables that provide socio-economic contexts of the consumers (and providers) I interviewed. Each of their stories highlight specific issues related to KanCare, but together, their voices suggest the problem is less that of KanCare alone but is more of health in the context of poverty in relation to how Kansas policymakers responded to it. The following is an account of what the consumers I interviewed knew about KanCare and their health care choices, and how they felt about it.

### **What Consumers Knew**

#### *Knowledge about KanCare*

What people actually know about their health plans, the differences between health care plans, and what options for care they have through Medicaid is telling. For instance, a survey comparing Medicare beneficiaries in four states enrolled in either a fee-for-service or managed



care plan showed that 30 percent of beneficiaries knew little about HMOs, about one in ten had adequate knowledge to make an informed choice, and HMO enrollees had significantly less of an understanding of the differences between managed care and fee-for-service than other beneficiaries (Hibbard, Jewett, Engelmann, and Tusler 1998: 181). “Appeal rights” and “emergency care” were not well-understood by most in the survey, for example. In addition, consumers did not understand cost implications, but even though HMO enrollees were more understanding than those in fee-for-service, only about half of HMO enrollees understood that they had access to more benefits and preventative care services and lower out-of-pocket costs than those in traditional Medicare. That is, having better care does not mean consumers *know* they have it, thus raising the question of utilization. The survey also revealed a positive correlation between knowledge scores and education and income, and it found that men and enrollees in traditional Medicare had higher knowledge scores (1998: 186). Participants in a focus group study of Medicaid consumers in Missouri were confused or felt uninformed about Medicaid eligibility issues, needed assistance with applying for Medicaid benefits, were unsure where they could receive help, and experienced poor communication (Zimmerman, LaPierre, and Brooks 2016). What this line of research shows is that consumers may have deficits in knowledge about their health care largely due to no fault of their own. Making informed decisions, therefore, can be troublesome, especially when consumers are left to navigate confusing processes on their own. The seven consumers I interviewed give insights into what Medicaid beneficiaries in Kansas know about KanCare in the face of the state’s effort to get the word out.

In light of the efforts by the state to inform consumers, this chapter seeks to understand what consumers knew about KanCare and how. Knowing how consumers comprehend a

complicated program like KanCare gives insights into what information consumers have at their disposal to both construct attitudes about Medicaid and to make decisions about their health care within the context of privatized managed care. The matter of knowledge in the healthcare marketplace is an essential factor to its efficient functioning. That is, market efficiency presupposes adequate knowledge.

Low-income persons often do not understand the intricacies or details of the policies that affect their lives, as research noted above might suggest, but this assumes that low-income persons, and therefore Medicaid consumers, tend to be less educated. It is instructive to note that, unlike the average Medicaid beneficiary, the consumers I interviewed, though mostly low-income, all had a college degree. This may have something to do with the nature of the disability population in relation to other Medicaid participants. So in fact, the consumers I met were an unusual group of people, and who I suspected would be fairly knowledgeable about KanCare. That did not quite turn out to be the case.

Most of the information consumers had about KanCare came from the one or two letters they received in the mail in late 2012 announcing the change and from the material they received with their new KanCare card. None of the consumers I met attended the public meetings held by the state about KanCare, though one did attend a community forum about it, only two visited the KanCare website, none had knowledge of the public service announcements, one provided personal testimony before the Kansas legislature, and no one read much of anything in news media about the new program. Consumers tended to be starkly divided along lines of their knowledge: two were very informed, one was somewhat informed about Medicaid in general, and the other four were largely uninformed about KanCare.

Consumers' mobility troubles might have influenced whether or not they were able to attend any of the public meetings, if they knew about them in the first place, but they never indicated that would have been a problem. However, they did have access to videos of the meetings posted online, but they did not know about them. Consumers like Michael, who is tech savvy, can navigate the online world (he and I communicated via email on numerous occasions), but others might not have similar skills. Michael is a white man in his 50's and suffers from muscular dystrophy. He is also a professional writer and advocates on the behalf of persons with spinal cord disabilities. Research does find that “people in most need of Medicare and Medicaid information online (the elderly and poor) are accessing it, and people with years of online experience are strong proponents of online searches” (Schmeida and McNeal 2007: 637), but about one-fifth of Americans still have no Internet access (Chen 2013: 20), which varies positively with SES. Zillien and Hargittai (2009) argue that SES, independent of other individual characteristics, makes a difference in *how* people use the internet, not just whether they have access to it. They contend that higher status people do more online to increase their personal capital than lower status individuals, meaning that for lower income Americans who do have internet access, they are less likely to use it to advance their knowledge about substantive issues directly relevant to their lives and in ways that connect them to others.

In fact, the two consumers that knew the most about KanCare were more engaged politically than the others. They gained their knowledge by doing research on what KanCare entailed in the context of being involved in the public discourse around KanCare, in one way or another. It was, in part, their connection to broader publics as concerned citizens that may have contributed to their improved their knowledge over others. For instance, what Agnes knew about KanCare was mainly from the KanCare website, but she said the website was “confusing.”

Agnes is a white woman in her early 60's who suffers from debilitating arthritis. She has had hip and knee replacement surgeries and struggles to walk and stand. Walking any real distance is painful, as is driving. She had also attended at least one public meeting about KanCare in which she made statements about her concerns and fears<sup>123</sup>. She explained that KanCare “is a managed care organization, it is for profit, for providing service to people who are in poverty who qualify through the state. There are basically three companies to choose from.” Whether she understood what 'managed care' means is uncertain. As one study showed, when asked, consumers enrolled in a Medicaid managed care program were relatively uninformed about “managed care” and what it entailed (Flores, Abreu, Sun, and Tomany 2004: 336). Consumers just want to know that when they are sick or need health care, they can go to the doctor, show their Medicaid card, and receive the care their doctor tells them they need. That was the sentiment consumers generally conveyed to me. However, if consumers do not understand their eligibility terms, how to challenge denied claims, or their rights, they may be at a disadvantage and their health may ultimately suffer.

The other well-informed consumer was Michael. He, like Agnes, knew that KanCare entailed contracting Medicaid out to three for-profit MCOs, would purportedly save the state money, and not cut provider payments or consumer benefits. Both had researched KanCare, but for different reasons. For Agnes, it was about the power of knowledge and so she would not “get taken advantage of” as she told me, but for Michael, it was because his health was at stake. His disability made attending public events about KanCare difficult, yet he still tried to remain engaged through the written word. To be effective in his advocacy, he had to learn substantive

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<sup>123</sup> I personally observed Agnes contribute her thoughts several times during what was a town hall meeting of sorts in an eastern Kansas community that was not part of the state sponsored public information campaign.

details about KanCare, such as the arguments for the reform and what changes were supposed to come with it.

Generally, though, consumers were not very knowledgeable about KanCare, why it was enacted, and what changes were to take place. Brian did have some general knowledge about Medicaid, but not about KanCare in particular. He is a white man in his late 30's who suffers from metastatic colon cancer. His knowledge of Medicaid stemmed both from his education in a health care field and from being a patient himself. As Brian told me,

“I know about Medicaid from pharmacy school, but I don't know anything specific of KanCare. It is the state's implementation of Medicaid. I know in general it is for people who need assistance who are not old enough to qualify for Medicare, who are people like me with something catastrophic, people in need, lower income.

He is aware that Medicaid in general is for low income persons, but does not realize people over 65 or people with Medicare can qualify for Medicaid as well. He could speak on Medicaid in generalities but knows nothing specific about KanCare, which I found to be the more typical case with consumers I interviewed.

The other interviewees were even less informed than Agnes, Michael, and Brian. Most were not clear on what KanCare entailed in relation to the old system, at least in a general sense, and were largely unaware of the extent of the privatization of Kansas Medicaid. To them, KanCare was largely a mystery. Being a KanCare consumer with a disability meant not just understanding their health plan but understanding the complexities of their health situations. That is, keeping up with their health and all that goes with it, like their insurance plan, is a lot of work.

Asking Robert about KanCare, he said “I am not sure I know very much. I haven't studied the thing. I don't know if there is much a difference [compared to the old Medicaid system]. I guess I am not very informed. It's like, I have some modicum of security. I am not on the street. I can feed myself.” Robert is a white man in his mid-60's, who never married, and he

suffers from severe anxiety and diabetes and has been unable to work since the 1980s because of his mental health. Like most of the others I interviewed, Robert did not attend any of the informational meetings for Medicaid consumers. “No. I kind of shun that. I keep to myself.” He did not know about the KanCare website either. “I should look that up.” His tone indicated that he was a bit embarrassed at not knowing more. Robert was more emblematic of the people I met.

Gary also had little knowledge of KanCare. What little he did know had mostly to do with the spend-down process associated with a Medicare beneficiary becoming eligible for Medicaid. Gary is a white man in his early 50's who has a PhD in philosophy and taught at a community college. He is a caregiver for his mother and met with me on her behalf. Gary's mother depleted her assets, including an annuity her late husband left her that supplemented her social security income. With her assets depleted, all that was left was to sell her house. The process of selling his mother's house was stressful and frustrating for Gary, because he felt as if though the state was not being forthcoming with much needed information. “It is as if they don't want to tell you on purpose!” He received help filling out forms from someone at the nursing home where his mother lived, because he felt he could get no assistance otherwise. At one point, he received a letter from the state saying that his mother would be dropped from Medicaid. He was shocked and did not know what he was going to do about his mother's care now that she was in a nursing home. Then a few weeks later, he received another letter stating she is being signed up with United Health Care under KanCare and advising when her new plan will begin. This contradictory information left him feeling uncertain about the future of his mother's care. Perhaps the miscommunication had something to do with the transition process from Medicaid to KanCare, but he felt no more informed after the implementation of KanCare than he did before

it. His sense of alienation from the whole process was apparent in his feelings of helplessness and stress of not knowing what was happening. For Gary, knowledge of KanCare, and what to do for his mother, meant a struggle to comprehend seemingly conflicting, and often absent information. His frustration is likely not too uncommon (Zimmerman, LaPierre, and Brooks 2016: 6).

Being well-informed is difficult, because just keeping track of the information consumers receive can feel taxing and overwhelming. While talking with Agnes, she brought out two giant three-ring binders crammed full of KanCare-related papers, letters, forms, and other sundry ephemera. I was taken aback. I asked her, “how are you able to keep up with all of that,” and she responded, “it’s difficult!” All the information was simply “overwhelming.” Good organizational skills help her maintain records of her health care experiences, a benefit of her education. For others, though, KanCare is daunting - but not for a lack of education. Robert said, “I feel very defeatist when it comes to these big government systems. I feel overwhelmed. That’s why I haven’t looked more into KanCare.” So even though he was interested in knowing more, he felt powerless. Gary, who is the most highly educated person I spoke with, also said he felt “overwhelmed” by the processes involved in caring for his mother and her affairs. So I can understand why some consumers seemed uninformed. In a sense, there might have just been too much information to process without going out of one’s way to systematically organize it. It might also have been that certain aspects of KanCare were just easily misunderstood in light of having little substantive knowledge of it.

What these consumers knew illustrates how complex something like KanCare might seem to people who are dealing with often complex health or care issues, despite being well-educated, and are not actively seeking knowledge using available resources. What the diversity

in knowledge suggests is that different consumers utilize different strategies to make sense of the social programs in which they participate. From some consumers' points of view, KanCare was largely a mystery, in part, because they were unaware of their resources despite the public awareness campaign led by the state and all the information about KanCare they received in the mail. The information they did have at their disposal seemed to not help them much, as evidenced by their responses to questions about different aspects of KanCare. When I asked consumers about care coordination, for instance, they had no clue really what that meant. Robert said, "oh yeah? How are they going to do that?" Or, when Gary talked about how he felt alienated, and like he was being left hanging when trying to figure out what to do about his mother's care. Their strategies were acquiescence or cynicism. Whereas those who were more actively engaged as concerned citizens, felt empowered at least to critique KanCare. Agnes, for example, had a better grasp of the role of her care coordinator, mainly because she was actively engaged in establishing a relationship with her. Michael knew more about KanCare's more substantive goals of improving care and saving money because of his activism. No matter how they dealt with the information they had, the issue was that consumers were tasked by KanCare to sort through information for a program said to result in "no change" for consumers.

From these consumers' perspectives, just having information available on a website, a letter, or through a public relations event was not enough for the state to ensure consumers would be informed. They needed help processing and organizing everything. The rational consumer model upon which Medicaid managed care in general, and KanCare in particular, is constructed presupposes informed consumers to function effectively. The consumers I interviewed understood their health needs very well, and unlike the majority of Medicaid consumers, they are well-educated. Yet, few really had a good grasp on the nature of the program, whereas others had



no concrete knowledge at all. From consumers' perspective, KanCare is overwhelming, daunting to comprehend, and engenders a sense of powerlessness, an unintended consequence of the devolution of responsibility.

Though they were all college-educated and most had been Medicaid beneficiaries for a long time, what set some consumers apart from others in terms of what they knew about KanCare was their community involvement. Michael's political action and his work in the advocacy community and Agnes's engagement in the public discourse, albeit not to the same extent as Michael's, informed their understanding of KanCare. They understood that health care for the disadvantaged is a social issue, not just a private problem. Their political action made clearer the connections of their individual milieus to the health care system that are obfuscated by the day-to-day life of poverty and illness, as the other consumers implicitly intimated. However, the other consumers were not active in public discourses and knew far less. Robert was concerned that he did not know more about KanCare, but the powerlessness that he felt in the face of such a daunting program hindered his understanding of KanCare. Gary felt the same way. Brian was just too busy, he said. With surgeries, treatments, doctor visits, filling out paperwork and paying bills, he just did not have the time to invest in learning more about KanCare. Similarly, Denise and Sarah, who were neighbors, dealt with the vicissitudes of their health on a day-to-day basis. For them, some days are better than others. Denise is an African-American woman in her late 40's, has a college degree and worked in social services for a few years, and Sarah is a white woman in her early 40's with multiple sclerosis and a degree in education who taught school for many years. What their lack of knowledge of KanCare illustrates is, on the one hand, the complexity of a confusing system saturated with information

that is difficult for some to process and is at times overwhelming, and on the other hand - and more to the point, the confluence of the constraints of poverty, disability, and illness.

In light of what consumers did and did not know and how they make sense of their health care, it is possible to begin making sense of what it means to be a 'consumer' in a private Medicaid managed care system in a capitalist society. What consumers know, but more importantly, what they perceive, and how they arrived at those perceptions, gives clues as to what being an 'informed consumer' is and how such a consumer makes certain health care related choices, given the range of choices they have or know. Since 'consumer choice' is one of the cornerstones of KanCare, it is important to explore what this means from the consumers' perspectives. As the consumers I interviewed show, consumer choice, as such, is problematic and warrants a closer look.

### *Knowledge about Choice*

I discussed what KanCare consumers knew about KanCare itself. In this section, I explain what consumers understood about their health care choices under KanCare after reviewing the medical sociology literature on consumer choice. After the *Goldfarb v. Virginia State Bar* Supreme Court case in 1975 ruled that “learned professions” like medicine are not exempt from antitrust laws, devolution of health care decision-making from the health care industry and government to individuals in the form of competition and consumer choice has grown (Havighurst 1986: 699). The American health care market treats people as consumers of health care commodities, including, increasingly so, home and community-based long term care services and supports under Medicaid, and less so as medical patients (Kapp 1999). The issue is that being a consumer “presupposes the active, attentive involvement of an individual who is capable, as well as desirous, of making and expressing autonomous purchasing decision” (1999:

295). Being a patient means you are being cared for by someone else, a medical professional or a family caregiver, and one can rely on experts, but being a consumer means the work of being a patient is more in the hands of the person who is sick or in need of services. The individual consumer is the expert on their care, a sentiment echoed by the Kansas Health Consumer Coalition in legislative testimony. A person must also want to, but then must also be able to, sort through health plan options, or hire and direct the work of an in-home care attendant, while also weighing options for treating an illness or pursuing various sorts of medical testing, for example. For certain Medicaid populations like children, some persons with intellectual and developmental disabilities, and some older persons, desire and ability are problematic. Thus, policymakers must consider how to determine if a person is capable of making proper health decisions, such as whether to use criteria for patient informed consent, or how to determine who a surrogate decision maker could be and how that person makes decisions on behalf of their client (1999: 296-98). In this ethos of choice, we assume people have information with which to make rational decisions among sufficient options.

Consumer choice assumes people have sufficient information and diverse options with which to make informed choices, but it is important to consider the nature of the information and options available if we are to understand how and why consumers make the choices they do. More choice may not necessarily be better, though policymakers and lay publics often think it is (Peters, Klein, Kaufman, Meilleur, and Dixon 2013: 116). As social psychological research on health care decision making shows, the realities consumers face may, on the one hand, be too much information or too many options, which can be overwhelming, resulting in poor choices. On the other hand, they may have uncertain or ambiguous information, which can make decisions difficult or discourage them from making a decision at all. Moreover, people may not

comprehend the meaning associated with information and choices provided, and they may not understand the significance of the outcomes of their decisions. Lastly, consumers may anticipate regretting a decision when they have options and select to do nothing (Peters, Klein, Kaufman, Meilleur, and Dixon 2013: 117-18). There can be a “tyranny of choice” for Medicare Part D consumers, for example, thus producing worse choices, lower satisfaction with choices made, information overload, decision-making anxiety, and unhappiness (2013: 120). Experimental studies show that “less is more” when consumers weigh comparative performance information to make hospital choices (Peters, Dieckmann, Dixon, Hibbard, and Mertz 2007). Therefore, just because consumers have information, they may not understand the choices before them unless information is selective and carefully crafted to emphasize meaning and ease cognitive burdens. I turn now to what information consumers find valuable.

While cost of care is at the center of political debates on health care, consumers do not always consider price when choosing doctors (Rice, Nelson, and Colby 1992; Sinaiko 2011). Cost is one factor in selecting health plans, but not the only one (Walsh and Fitzgerald 2012: 21). As noted above, some consumers may not even understand the cost implications of different care options. Therefore, people weigh concerns other than price when it comes to their health.

Consumers often prefer informal, qualitative information from friends, relatives, and acquaintances (e.g., word-of-mouth) when making choices among health care providers or health plans, with advice from non-professionals often outweighing that from experts (Huppertz and Carlson 2010: 1602, 1605). A 2008 survey of one state’s Medicaid consumers found that 36 percent of beneficiaries used heuristics to determine choice of managed care plans, citing a “more is better” justification for selecting a health plan they thought provided more benefits, while 23 percent chose a plan because it met a specific need (Walsh and Fitzgerald 2012). Few

(6%) reported choosing a plan because of expert advice and almost none cited friends or family referrals, contradicting other research (2012: 26). Almost two out of ten did not elect to make a choice of plans. When required to make a choice between two primary care physicians, one experimental study showed that people gravitate to technical quality over interpersonal quality of the doctors, though a significant proportion preferred a doctor with high interpersonal ratings (Fung, et al 2005). Some consumers, especially those of low SES and with chronic conditions, want nurses who educate them on their illness, treatment, medication, and staying healthy, who spend time with them, who are well-informed, and who communicate well (Oermann and Templin 2000). Consumers also want to assess how well health insurance plans perform on preventative care and consumer satisfaction (Hibbard and Jewett 1996), and consumer reports of health plan quality do matter for selecting a health plan (Spranca, et al 2000), but how well consumers understand performance measures and other quality information varies.

Many consumers do not often understand objective quality indicators that are sometimes provided (e.g., rates of mammograms and cholesterol screenings) and thus view them as less helpful in comparison to patient quality ratings (e.g., doctor communication and respect given to patients) which consumers tend to understand better and see as more helpful (Hibbard and Jewett 1997). Focus group research by Jewett and Hibbard (1996) found that Medicaid beneficiaries and the uninsured are less likely to understand quantitative data, ask questions or seek information about quality indicators than the privately insured, and that they are more likely than the privately insured to think certain health conditions (e.g., death, cancer, hospital infections, low birth weight) are unavoidable, seeing little efficacy in prevention.. About a quarter of all comments made in their focus groups reflected low comprehension of quality indicators, though comprehension varied with insurance status (i.e., privately insured, Medicaid, uninsured). Jewett

and Hibbard (1996: 85) argued that, despite policymakers' assumptions to the contrary, consumers make few connections between health plans and quality of care, instead seeing quality as related more to the doctor-patient relationship. A survey<sup>124</sup> of Florida Medicaid beneficiaries enrolled in a new pilot capitated managed care plan in 2006 found that enrollees had difficulty understanding plan information and components of the reform, and they saw little difference between plans and had difficulty choosing between them (Coughlin, et al 2008). One in three did not even know they were enrolled in a new program despite receiving a letter advising them of the reform and to select a health plan (Coughlin, et al 2008: W524). What this implies is that simply giving consumers information and choices is not enough. Policymakers have to consider the fact that some people do not interpret information the same way, which then has implications for the kinds of decisions people make – decisions that might not be what policymakers have in mind to reduce costs and improve health outcomes.

Interestingly, a recent nationally representative poll conducted by the Kaiser Family Foundation (2015) suggests that people do not usually use information on price or health plan, provider and hospital quality, citing that costs can be hard to find and that they have not seen quality information or would have used it to make health decisions (Altman 2015). Even though quality information is more readily available, people have been using it less over the years (Kaiser Family Foundation 2008). Consumers perceive little difference between hospitals in their communities, and instead they may rely more on mere familiarity with a hospital or personal referrals for surgeons rather than quality ratings (Kaiser Family Foundation 2011). People tend to be passive recipients of care and not active consumers seeking out and comparing information to make the most informed, rational decisions, especially among those who are of poor health

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<sup>124</sup> Kaiser Commission on Medicaid and the Uninsured. "Florida Medicaid Reform Waiver: Early Findings and Current Status." Retrieved July 12, 2016 (<https://kaiserfamilyfoundation.files.wordpress.com/2013/01/7823.pdf>).

status, with higher levels of service utilization, and strong ties to particular providers (Harris 2003: 711). Since health policy today, including KanCare, emphasizes quality of care, especially with greater utilization of MCOs (Snyder and Rudowitz 2016) and patients as consumers, it is important to note that consumers may not be motivated to make health decisions based on factors policymakers intend. There are other, more subjective, factors driving consumers' health decisions that policymakers might be overlooking.

KanCare emphasizes the freedom it gives Medicaid consumers to choose: to choose their own health insurance plan and to choose their own doctor. The experience is supposed to mimic the private health insurance market. One of the three KanCare MCOs, Sunflower, for example, advertises on its website that it has “a large listing of providers to choose from.”<sup>125</sup> Another MCO, Amerigroup, says, “[m]ore doctors, clinics and hospitals join our network every day.”<sup>126</sup> As an aside, this does not mean, though, that more providers overall are accepting KanCare, rather that providers that accepted Medicaid before are now signing up with Amerigroup or Sunflower. The idea is that consumers can select the plan their health care providers accept and meets their needs.

To make the plans more competitive, KanCare MCOs provide value-added services that are supposed to be criteria on which consumers can base their decision to choose one MCO plan over another. These value-added services, a package that varies somewhat between the three MCOs, can include adult dental care, a cell phone for medical care use, or incentive programs for behaviors that promote good health such as smoking cessation. The specific services vary between MCOs, but all are paid for by MCOs at no charge to Kansas taxpayers or KanCare consumers, which make them 'value-added.' These services are intended to encourage

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<sup>125</sup> <http://www.sunflowerhealthplan.com/>.

<sup>126</sup> <https://www.myamerigroup.com/ks/pages/welcome.aspx>.

prevention, which in theory, reduces the overall cost of Medicaid and improves consumers' health. Thus, consumers can choose the plan that they feel works best for their situation, needs, and wants. In fact, some consumers did switch their plans in that initial 90-day open enrollment period. Each MCO received approximately 120,300 members in the initial enrollment, but after the 90-day choice period, the distribution changed slightly with Sunflower receiving a greater proportion of consumers (Sunflower: 36.7%; Amerigroup: 32.1%; and United Health Care: 31.2%).<sup>127</sup>

Did consumers exercise "choice" by changing plans? Interestingly, not everyone knew they even had a choice. Some consumers were ambivalent about being able to choose plans, while others did not realize they had a choice, as Brian explained. "I don't recall anything about a choice, or reasons why I should choose. That would stick out in my mind. I am one of those people who would spend hours comparing plans." Or, they were uncertain about making such a choice at all, as Robert indicated. "Well, I was not really indifferent. I just feel overwhelmed by a system that treats me as part of a machine. I get overwhelmed." He did not express wanting to be with one MCO over another or indicate reasons why he would choose one MCO over the others. Rather, Robert felt powerless about the whole thing. Only one consumer, Agnes, changed her plan from the one she was initially assigned after KanCare came online. Thus, consumers had mixed feelings about the option to select an insurance plan, from a desire to consider their options rationally, to apathy, to feeling beset.

Like other consumers throughout Kansas, Agnes changed her plan. I asked her why she changed it, and she said that her choice was not because of some incentive program or a value-

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<sup>127</sup> Presentation by Effie Swanson, Kansas Department of Health and Environment, Division of Health Care Finance to the American Academy of Pediatrics Kansas Chapter on April 19, 2013. Retrieved September 10, 2015 ([www.kancare.ks.gov](http://www.kancare.ks.gov)).



added service offered by the MCOs, as I had anticipated. Agnes exclaimed, “[t]hose value-added services are making me scream. They are just a joke. I do not use value-added services to shop for an insurance company . . . It seems like they were programs for young people, children.”

Indeed, she was skeptical of the value-added services offered by her first MCO, United Health Care.

[United Health Care] discourages people from using the value-added services. They make you think you are eligible for them, but half of them you are not even eligible for. United Health Care said you have to be homeless to get a cell phone. Sunflower, that's my current one, 'we do those government cell phones.' I see my neighbor has one of those government cell phones, and she says it breaks down all the time. She's coming over to my house to use the phone.

Although consumers may doubt whether MCOs provide value-added services, MCOs are under contract to provide these services at no cost to the consumer, or the state, and MCOs rely on those services to encourage prevention and responsible health care to help meet their performance standards. The issue is how a consumer might perceive such services, if they knew about them in the first place, which most consumers I talked to did not. For those that do, like Agnes, they did not make any difference. “So one company can have the best value added service in the world - and that looks like Amerigroup, they have awesome value added services - but none of my providers are covered so I rejected them.” Agnes said that she did look at the value-added services, but “if you cannot get medical care, continuity of care, then what's the point?” Instead, having access to her preferred provider was more important to her than what amounted to gimmicks, from her perspective.

For some consumers, having a choice, though in theory was good, was of no practical concern, such as was the case with Brian. “In some ways, it does not matter in my circumstances, because the hospital was nice enough to do a 100% write-off, so I got into Medicaid so the hospital would be reimbursed for what they had given to me.” His

contentiousness partly informed his “choice” more so than any sort of competitive features of any of the MCO plans. He did not have a preferred doctor and cared little about optional services to improve his health, considering the nature of his cancer. Plus, he already thought he lived a rather healthy lifestyle. Most importantly, though, for him, the acute urgency of cancer, along with the mounting medical bills exceeding a quarter of a million dollars, provided the primary impetus for enrolling in KanCare and remaining with his current plan.

Being able to choose their own provider was another benefit to consumers and did make a difference to some, but for most that was not an issue. Since health care providers are not required to accept Medicaid, or KanCare specifically, some consumers may encounter difficulties in receiving the care they need from the provider they want, which was one of Agnes’s biggest concerns. Robert talked endlessly about how he wanted to be able to see a private psychologist instead of someone from the community mental health clinic nearby. “I don’t like going to [the community mental health center], because they just want you to conform. They don’t treat you like an individual.” He despised community mental health, and he felt stigmatized by the ‘welfare medicine’ undertone to it. He wanted to be treated like a unique person, which he felt that he did not receive in the community mental health setting. The problem that Robert encountered is that few private mental health providers accept Medicaid in Kansas, at least those that are near where he lived; therefore he, like many other KanCare consumers, have a very narrow range of choice of provider.

While Robert felt he had no choice regarding his mental health care provider, Agnes did have a choice and went with the plan that all her doctors accepted. Having continuity of care from the old system to the new was a key factor in Agnes’ choice in selecting a plan. Making

sure all providers accept the same insurance plan was a problem that some consumers had to resolve, though for most of the consumers I interviewed, that did not seem to be an issue.

Agnes's story does give some insight into why consumers might choose one plan over another, when the choice is meaningful. Along with choosing a plan that allowed for continuity of care, another factor that influenced her decision to change plans was quality of her relationship with her MCO. “Now with KanCare, I seem to be having better luck with that. The second insurance company - I was skeptical, I was really skeptical - I've turned out to have a good relationship with them. That part seems to be better than with the old system, because I can just call them up, the care coordinators.” Agnes liked how accessible her MCO was. She said that she had problems with her first MCO, United Health Care, and changed plans. She told me that the first MCO representative relationship was too impersonal, but after she changed plans, her new MCO sent a case manager to her home, which she really liked. She said that her first case worker told her that she had over 100 consumers in her case load. With a caseload of that size, Agnes said, the lack of a more personal relationship was not surprising. She said that she was much happier with the other company, Sunflower. Her choice had more to do with the quality of the relationship she had with her case manager than with the benefits offered by either MCO.

When choice made sense, the quality of interpersonal relationships with case workers mattered, though that alone might not lead consumers to make any changes. Choice may be more informed by one's sense of empowerment, as in the case of Agnes, or lack thereof, as in the case of Robert, rather than the objective existence of choice and incentives. Despite the importance policymakers placed on the issue of consumer choice and competition in the Medicaid marketplace, these consumers did not seem too concerned about it. Selecting an

insurance plan or a preferred provider were of little concern in light of other problems in their lives. Rather, continuity of care, choice of provider, and quality of the consumer-MCO relationship were the only factors that seemed to matter in deciding on which insurance plan to choose, at least for those who expressed any concern at all or knew they even had a choice. What consumers reveal is that health conceptualized narrowly as a function of consumer choice and incentives obfuscates the social basis of health and the meaningfulness of what consumers do to improve their lives.

### *Knowledge of Changes*

The third theme is knowledge of changes under KanCare. The consumers I interviewed noticed little change in Medicaid after the implementation of KanCare beyond receiving a new insurance card in the mail. Sometimes they even struggled to remember who their MCO even was. However, there were two notable exceptions. First, Michael told me that “under new managed-care rules in Kansas, I face a 76 percent drop in care, a move doctors say is wildly unrealistic and a move my wife says will force her to file for divorce and as a result, tear our family apart.” Cutting the hours of professional in-home assistance he receives, care which he said his doctors said he needed, would diminish his quality of life. Cutting of services was a fear I consistently saw coming from disability rights advocates in their legislative testimony and in the media, and Michael's case was the exemplar of those fears. Fortunately, the state reversed its decision and he was able to continue receiving the care he needed. I cannot say Michael's case was something to generalize from in terms of a pattern of change under KanCare, but it is an example of what potentially can happen when there is an emphasis placed on efficiency and cost savings in Medicaid despite the judgment of medical professionals who know their patients' needs. That is, when there is a conflict between the expertise of providers and that of the goals

of policymakers. Michael's experience was meaningful to him and colored his perception of the whole system, but it also created a context for political action and an opportunity to give voice to fears that might otherwise have gone unheard.

Second, another important change under KanCare is the elimination of co-pays for prescription drugs. This was something consumers noticed. For instance, as Robert explained,

The medications I take are really expensive. Now they are giving it to me without a co-pay at all. I was surprised that my co-pay going down to \$0. Have you heard that? [...] I don't mind paying a little bit out of pocket. It just seems kind of strange. I could raid the pharmacy for what I want, if the doctor cooperates. It used to be \$3. That would end up costing me \$40. I have a lot of medications.

The eliminations of copays is a positive benefit of KanCare for people with limited incomes, because Social Security Income does not provide much money. But Agnes was not so sure. "I was told that if I left the disability waiver and got on straight Medicaid, that I would have all these co-pays. I even asked my pharmacist and he says that some people have co-pays and others do not." So there seemed to be some confusion about co-pays.

Consumers seemed to notice little else in terms of change. Some did not know about the increase in choice, as they explained earlier. Robert, though he did not really understand "care coordination" as such did explain that he was happy about how his diabetes doctor coordinated with another doctor. Agnes felt the nature of the relationship she had with her MCOs under KanCare was not markedly better, considering the transition from case workers with the state who knew her to individuals she did not know, who had more cases than previous case workers under the old system, and who were bound by a different set of rules and processes that they were still learning. No one else other than these three consumers noted anything about change or lack thereof.

The interviews showed that consumers knew little about KanCare itself. They made choices based on subjective factors such as interpersonal relationships, cost, and necessity. In a way, some of the consumers did not perceive a choice in plans or providers due to their material or health circumstances. Finally, there was inconsistency in what consumers saw changed under KanCare, which may have been due to confusion. In the last section, I discuss what consumers thought of KanCare, given what they knew about it, which was not much.

### **Consumer Evaluation of KanCare**

Some research suggests that Medicaid beneficiaries have more negative experiences under managed care systems than the traditional fee-for-service models. Pina (1998) found that poor single mothers in California reported difficulty in gaining access to health care and less satisfaction with the care they receive from their HMOs. This line of research indicates that managed care does not adequately meet the needs of the poor. Indeed, as Pina argues, factors such as “poor housing and sanitation, inadequate diet, general family stress and hardship, social isolation and environmental hazards,” should be considered when assessing the health needs of the poor (1998: 434). The consumers I interviewed expressed many concerns along these lines. In Missouri, some consumers preferred traditional Medicaid over a private managed care plan. They experienced problems with access and disruptions to relationships with providers because of the convoluted managed care arrangements (Zimmerman, LaPierre, and Brooks 2016: 11-13). In their study of KanCare consumers receiving long term services and supports conducted between April and August of 2013, Hall, Kurth, Chapman, and Shireman (2014: 5) found that

Despite an overall satisfaction rating of 64%, a number of important issues were raised related to provider networks, covered benefits, transportation, communications, and care coordination. Within these broad categories, lack of disability cultural competence and awareness of a range of accessibility issues were especially problematic.

Almost 10 percent reported that their benefits had improved while 13 percent reported their benefits had gotten worse under KanCare (2014: 2). In other words, most consumers saw little change under KanCare.

Despite some of the concerns raised above, consumers in this study were generally positive about KanCare and did not express many of the complaints the survey by Hall, Kurth, Chapman, and Shireman found, except for transportation issues, communication, provider networks. Robert was happy with not having to pay a co-pay for prescription drugs anymore, for instance. Others expressed more nuanced concerns. As Agnes said,

I like the new system better, except for with the physical disabilities, disabilities in general. It's hard to get help. They want to pay for stuff that won't help me, but that was the same with the old system too. But with the new managed care, I did the research. So I guess I was neutral. You have to be more proactive under managed care.

For Agnes, the more she learned about KanCare, the more she liked it, with some exceptions. She recognized that to learn more, one has to do the requisite work, because she felt, as did others, that the state was not being as forthcoming as they would have liked.

When asked about their hopes and fears about KanCare consumers tended to be hopeful. They wanted the new program to work, which was interesting considering most did not really understand the difference between the old and the new system. Yet, when asked if they felt empowered to improve their health or to take more responsibility, they overwhelming response was “no.” On the one hand, then, consumers were positive about KanCare, on the other hand, they were not certain that it was the answer to their needs.

## **Conclusion**

In this chapter, I examined the state’s KanCare public information campaign of 2012 and 2013 framed as part of the KanCare legitimization process. I explored what consumers actually knew about KanCare after implementation of the reform in relation to the state’s effort to get the

word out about KanCare. Interviews with KanCare consumers gave insights into how knowledgeable they were about KanCare, and how they learned about it, what choices they had and why they made the choices they did, and what changes to Medicaid occurred under KanCare. Knowledge is critical for the consumer choice paradigm, but what I learned from consumers is that public information campaigns might not have been sufficient for getting the word out to the public about KanCare. The most civically involved consumers, the ones who actively sought information, were those who knew the most about KanCare. It was not that other consumers did not care or were in some way apathetic, but that they were overwhelmed by the complexity of Medicaid and their own personal troubles. There might be such a thing as too much information as previous research suggests. From what consumers told me, assuming that holding public meetings in centralized locations around the state, putting ads on the radio or on a billboard along the interstate, and sending literature in the mail is sufficient to reach most consumers is problematic.

The changes consumers noticed varied case by case, but what this might suggest is that the method by which the state informed consumers was likely not the best method for doing so. Consumers felt they were left with piecemeal information and inconsistent details of the new system. How we as researchers can reliably assess consumers' satisfaction in this context should warrant caution. Consumer satisfaction surveys, for instance, may suffer validity problems if there is inconsistent understanding of KanCare and all of what it entails from consumers' perspectives. This also raises concerns for proper evaluations of KanCare. How can we know the program is effective when there is inconsistent knowledge across consumers? Moreover, if information is central to the consumer model, and if the consumer models' success is necessarily tied to what people know, then the information problem by definition creates a problem for the



consumer model and any success that it could have. Can consumers make the sorts of informed choices policymakers expect? These are concerns that researchers attempting to assess KanCare should consider.

What these few consumers told me about KanCare, or what, in fact, they did not tell me, suggests that under the consumer choice and personal responsibility paradigm, the state expects consumers to know and do more. The state expects consumers to know what benefits KanCare has to offer, what choices of health care providers and insurance plans are available to consumers, what changes occurred under KanCare, when to use primary care, specialist care, and emergency care, and how best to manage their care with all the resources available to them. More importantly, the state expects consumers to acquire this information and then use it to make good health care decisions with the assumption that this information is all consumers need to provide for their care. It is not that expecting consumers to know certain things and act is a problem, per se. The question is to what extent do knowledge and opportunity matter for people in the context of poverty? Is knowledge and choice the only problems consumers face, if these are problems at all from their perspective, or do they deal with issues that policymakers do not consider relevant to health? What, then, are the implications of expecting more from consumers facing constraints of poverty? Are there implications for their health care providers? I will explore the outcomes of KanCare for consumers and providers in the next chapter.

## CHAPTER 5

### Problems of Work Transfer

#### **Introduction**

The purpose of this chapter is to understand how KanCare affected consumers and providers. Interviews with seven consumers and ten providers from different sectors of care underscored their common experience of health care devolution under KanCare. In their own ways, providers experienced an increased amount of work and consumers indicated an increased level of responsibility, a process akin to Nona Glazer's concept of 'work transfer.' KanCare expects consumers to take on more responsibility for their care and tasks providers with more of the administrative burden of ensuring Medicaid patients receive the care they need. Their shared experiences gives insights into the problems of work transfer, and what those mean for the provision and consumption of care in Kansas in the contexts of poverty and an ideology of self-sufficiency and personal responsibility.

The chapter begins by explaining the work transfer concept and how it applies to the current study. It then explores problems of work transfer first for health care providers and then for consumers. The provider perspective offers a unique lens through which to understand KanCare, a perspective often missing in sociological research on Medicaid. Health care provider

responses to the unintended consequences of Medicaid managed care gives insights into how the privatization of Medicaid delivery affects the poor (Lamphere 2005; López 2005; Nelson 2005; Willging 2005). As the chapter will explain, providers stressed the extra work they felt that they were responsible for since the implementation of KanCare – not just complaints about unwanted changes – but an increased level of responsibility for making KanCare work as policymakers intended. As for consumers, they did not readily parse out their health issues separate from other concerns, and they tended to not be interested in the contours of health policy. Rather, problems of housing and social environment, constrained income and work opportunities, and social isolation were obstacles these consumers faced as they contended with their various health issues. That is, they did not understand their health apart from the poverty they experienced. Yet, for these consumers, the hurdles they had to overcome did not keep them down. Each in their own way employed strategies to maintain their health and improve their quality of life *despite* their dependency on the state – a status they did not like. Their strategies highlight the importance of personal agency as a means for mitigating stressors that negatively impacted their health, as theorized in the stress process model of health. These strategies constitute work consumers did in spite of calls for more responsibility on their part. In other words, work transfer for consumers entailed a shift in responsibility from the state to consumers, while providers took on an increased workload just to make KanCare work for their patients.

### **Devolution in KanCare as Work Transfer**

The story of KanCare raises questions about devolution in health care and the implications for consumers and providers. Is the work of health care knowledge and of meeting care needs more in the hands of consumers than state case managers under KanCare? Is the administrative work of KanCare more in the hands of health care providers than government

bureaucracies under the old system? Interviews with consumers and providers suggest that the state is shifting work onto consumers and providers, a process that is akin to Glazer's (1990: 483) notion of 'work transfer.'

Glazer argued that in contemporary American society work is gradually moving from the paid labor of medical experts, usually men, to the unpaid labor of family caregivers, usually women. It is an application of rationality to irrational social processes. In the retail sector, self-service replaced paid professional clerks, placing the onus of consumption on the private individual and not in the hands of the sales expert, so to speak. Rationalizing the health care system entails shifting nursing and other medical work from professional staff to family caregivers (women), or the individual patient, to save money and increase profits. Part of this process is educating patients on how to properly care for themselves or training family members to provide care in the home (1990: 490). At the core of the work transfer process is a melding of the public and private spheres into complex social relationships that reinforce capitalism's dependence on the "semivisible" unpaid labor of women (1990: 494) and the success of corporations to reorganize the health care system to focus on care in the home. That it has not prompted organized resistance, Glazer says, is evidence of capitalism's hegemony in the social organization of health care and the redefinition of people's responsibilities for care (1990: 495). Her concept can help theorize the shifting of responsibility, work, and cost under KanCare. Though Glazer's observation has implications mainly for gender relations in modern capitalist society, I argue that the core of her argument – a shifting of responsibility and work from a higher status group paid for their labor to a lower status group who are unpaid – can help explain what I have observed in my research on KanCare. There are essential similarities and differences.

One similarity is that under KanCare, patients are now consumers. The work of being a patient, if we take Talcott Parsons seriously, has historically been partly the responsibility of the patient. The patient has always been expected to seek out care and follow doctors' orders, but the patient role is deviant and the work involves efforts to bring the individual back into conformity. Moreover, the physician as expert and authority on health matters goes unquestioned in Parsons' view. Under KanCare and the consumerist paradigm, the patient now consumer is an active agent in the health care market making decisions for her health, based on her own knowledge of her needs and options, weighing the choices available, and making the 'correct' decisions. She is a free actor in a marketplace, which is normal and expected in a capitalist society – not deviant. The consumer 'shops' for the right health care products and services. Yes, the physician retains authority and expertise, but the consumer, in the words of the Kansas Health Consumer Coalition, is an "expert" in their own care and so their voice matters. It is as if the consumer and the physician are more or less equal actors in the health care marketplace that come together in rational exchanges when the consumer chooses. The health work a consumer does is in addition to what he or she already does to maintain wellbeing, a potentially taxing endeavor for people living in poverty who might not have the cultural health capital to adequately care for him or herself. For the consumer, it is about having access to resources one can choose to use, not so much services and care given to a patient by a health care professional. While dealing with the vicissitudes of poverty and all the decisions that come with them, the consumer is expected to take on additional work of self-care (e.g., nurse hotlines, smoking cessation programs, extensive information consumers receive in the mail and have available online, transportation services). The next two sections develop first the themes of work transfer that emerged from interviews

conducted with providers in 2013 and 2014 and follow up phone calls and emails in late 2015, followed by themes of work transfer from consumer interviews in 2013 and 2014.

### **Work Transfer under KanCare: The Provider Experience**

After the implementation of KanCare, I met with ten health care providers to ask them about their experiences under the new system, and how they felt about it. Interviews gave me a sense of provider attitudes toward health policy in Kansas, including KanCare, and what some of their biggest concerns were. Three major themes emerged from the interviews around KanCare's stated goals: provider's views on health outcomes, quality of care, and costs. Providers were not convinced that KanCare would achieve its goals, though they did not want it to fail. They hoped it would work out in the end. In talking about their frustrations, their fears, and concerns about KanCare as it evolved, providers spoke about different ways they felt that they were having to do more than before just to make KanCare work. Their stories told of experiences of work transfer.

#### *Health Outcomes under KanCare*

Under KanCare, health outcomes are supposed to improve as the result of increased personal responsibility, consumer choice, and care coordination. Providers like Kristen, the director of a grassroots organization that helps persons with disabilities, tended to agree. "We need better care coordination, preventative care, and to use the system properly." When consumers act more responsibly, such as choosing primary care over emergency care, when they have choices of health plans, and when their care is better coordinated to ensure the right care at the right time, health outcomes for consumers should improve overall. The state claims that health benefits are already being realized in terms of people receiving care services they did not have access to before KanCare, such as bariatric surgery and adult dental care, and that emergency room visits have declined while primary care visits have increased. However, any

claims of health benefits would have to come with serious caveats given the time frame. As Gayle, the director of a non-profit community oral health clinic, stated, “[i]t might be difficult to come to any conclusions about whether KanCare is improving health outcomes, because it is so early.” Three subthemes emerged on the issue of health outcomes from provider perspectives. Providers weighed in specifically on responsibility, care coordination and adult dental care.

*Personal Responsibility: Provider Perspectives*

The concept of consumer responsibility was a key aspect of KanCare, and thus important to explore from provider and consumer perspectives. Provider responses varied, but most noted the limitations of the concept. Rachael, for instance, was cynical. As a director of a community health center in southeast Kansas that provides care for Medicaid consumers, she did not see how the paradigm had changed. From her experience, consumers have no more reason now to act any differently than before reform.

Medicaid has been paternalistic. Don’t see how KanCare changes that. The value added services, such as weight loss programs, are gimmicky. Patients are not incentivized. If a doctor tells someone to exercise, it is more likely to help than what KanCare is doing. There is no incentive for individual responsibility.

Lauren, the director of a community health center, agreed. Of personal responsibility, she said it was “great, but we have to help educate on what that means. It is changing a way of thinking.” Yet, she did not see how KanCare was accomplishing this. Gayle was unconvinced, too. To her, the problem for consumers was not that people just did not act responsibly, but that the problem is cultural and what people know and value.

Honestly, I doubt it. I don't know how they'd do that. I feel like a lot of it is education. People need to be more aware of what the direct correlation between poor oral health and overall health is. I don't know if that is a component for KanCare. That has to start when people are really young. We do that, because we have a large outreach program in [different schools in the area]. We catch kids that are otherwise not getting to the dentist. Maybe they have Medicaid, but their parents can't afford to take time off of work. They don't value it themselves, so they don't see it as something important for their children.

Any opportunity we can get to get them in the chair to do their cleaning and checkups, we try to educate them as much as we can. I don't know how KanCare would change that.

Eric, the director of another community health center, concurred. He did not see how asking people to be more responsible would help.

Providers talked of the limits of personal responsibility. Cindy, a billing manager for a non-profit in-home care organization, thought that consumers “should take more responsibility, but many don’t know what to do.” As Nancy, the owner of a physical therapy clinic, argued, “people don’t understand their health problems. And the health care system is so complicated.” Perhaps if consumers were better educated on proper care, but Medicaid for some consumers is “overwhelming,” with “too much information sometimes.” Kristen explained how consumers are inundated with information. Information is good, but it is a lot of “mail for consumers.” Many “don’t open their mail. And phone calls? They don’t return calls.” Consumers are “overwhelmed with the day-to-day.” Her observations reflect what consumers said in the previous chapter about how they felt overwhelmed or that the information they had was too confusing.

As far as providers could tell, as Lauren observed, “nothing changed” under KanCare to challenge any of these limits or to empower consumers to seek better care. If anything, KanCare created more obstacles to improving health outcomes for both providers and consumers according to some providers. As Rachael explained,

It is “rationed care.” The reason KanCare is rationed care, is because of the levels of approvals and pre-authorizations. KanCare is reducing utilization. Patients might not have a phone or transportation. It creates barriers to the poor. This is why I call it rationing. Because of the barriers created.

The issue of authorizations is something I will discuss in more detail below. Her fear is that with obstacles she feels is being placed on providers and consumers in terms of increased red tape or absence of improvements to health care access, KanCare will make it more difficult for people to



utilize services, which could have a negative impact on their health. She recognized, as did other providers, that the poor already face numerous obstacles to health care, but that KanCare did almost nothing new about them from their perspective. There was one change, though, that providers agreed should improve health, if implemented properly, and that is better care coordination.

### *Care Coordination*

Views on care coordination were mixed. The idea itself is good, but how it has played out under KanCare raised questions for these providers. As Nancy explained

I think care coordination is a good thing as long as it is not a euphemism for limiting care. I think care coordination helps, because people do not know how to manage the health care system, and they wait until they are very sick and go to the emergency room, which is a problem. A case manager can help teach people how to better manage their own care so they are not putting off going to the doctor that they could take care of on a Friday afternoon instead of going to the emergency room on Sunday night. I think managed care is to limit testing. They are managing by numbers. That is what they are good at. Managing is not necessarily medically driven, but driven by the plans' idea of what is too much, or whatever.

Rachael was more skeptical of KanCare coordinating care. "I don't see how it can [affect health outcomes]. Case managers are not truly managing care. Health homes are coming out soon and will have actual case management...should have quality improvements. KanCare is just a reimbursement system." One way health outcomes were supposed to be improved by the managed care plans was through the establishment of 'health homes.' This was the case management function of the MCOs that would help coordinate services for consumers, such as between their primary care physician, mental health provider, pharmacy, etc. Given that the health homes had yet to be implemented when I conducted these interviews, the sentiment at that time was that there was no real care coordination, and that it was more rhetoric than anything else.

### *Dental Care*

A new benefit for adult KanCare consumers is dental care. Prior to 2013, only children received oral health coverage under Medicaid. Now, each of the three MCOs offers a dental care package available to children and adults, but the plans are fairly similar. On the surface, this seems like a great idea. Oral health is often treated like mental health, as something subjacent to physical health of the rest of the body, but research clearly shows the importance of oral health for overall health, subjective wellbeing, and perception of hygiene and class status (Exley 2009: 1094). As Gayle said above, part of the problem with oral health is education and culture. “These are people that have not seen a dentist for more than five, ten years or more, unless they have an issue with pain or an emergency. In terms of prevention, they have not taken care of their teeth by going to the dentist for regular cleanings and checkups.” Individuals need to understand how important oral health is, and that in American culture, oral health needs to be valued more, hence her clinic’s public outreach program in schools, for instance. “Any opportunity we can get to get [kids] in the chair to do their cleaning and checkups, we try to educate them as much as we can.” From a policy perspective, though, it is a little more complicated.

Two MCOs offer two dental visits per year, and one MCO offers one visit per year.

However, there is a problem.

For adults, they are now covering one code of preventive services, which is just a general prophylaxis. And I am not quite sure why this is being covered, but they are covering the bleaching of one tooth, which is the silliest thing I have ever heard. I think what it was designed for is if you had a root canal and it's discolored. They'll cover the cost of the bleaching. The funny thing is that would assume that a person with Medicaid would have been able to afford to have a root canal in the first place, which they can't because a root canal is not a covered service. So the bleaching of a tooth is completely cosmetic, and I don't understand why they're covering that.

Beside the almost pointless nature of the tooth whitening benefit, as Gayle saw it, the general prophylaxis, which is the standard cleaning that many Americans receive twice a year

when they have dental insurance, is almost just as pointless it seems. “The problem has been that very few, probably less than five-percent of the adults with Medicaid that have come in and inquired about having a cleaning done, need something far more extensive than a basic prophylaxis.” The kinds of health problems that come with not going to the dentist regularly and not practicing good oral hygiene are not covered by KanCare. “They need a scaling and a root cleaning. They have severe periodontal disease.” More often than not, Gayle says her clinic is unable to help adult KanCare patients. “[Consumers] leave feeling angry and frustrated thinking they will be able to, in who knows how many years, to have a teeth cleaning, and we can't do anything for them because what they need is something Medicaid won't pay for. And they can't afford to pay out of pocket for that service. So it hasn't really helped anyone.” About 95 percent of adult consumers she has to turn away, because they have health needs KanCare will not cover.

It was a good idea to extend dental care benefits to adult consumers, but there are problems. “In theory, the provision of that service sounds like a great thing, that it is going to help this population access preventive care, help long term health outcomes, because they're getting a regular exam and cleaning twice a year, but if that is not what they need, it doesn't do them any good.” Her perspective suggests that if the state had a better grasp of people actual health needs, then the dental coverage might be better. Instead, it places such limitations on providers that the policy is rather ineffective and just looks good on paper. This issue is an example of why policymakers should include providers in the initial development of health policy.

So as far as health outcomes are concerned, these providers did not see a positive impact yet, or see really how there would be. Personal responsibility comes with caveats. The system is still paternalistic, it does nothing to change values or knowledge. It ignores the role of providers

in managing care, and overwhelms people with too much information that can be difficult to keep straight. They understand that consumers should do the best they can to take care of themselves, but they are aware of the obstacles many face, whether from poverty or disability, or both. They do not see the personal responsibility discourse as very helpful. Instead, as providers, they want to do what they can for their patients, no matter what patients do for themselves. In fact, they want to provide quality care to consumers, but they are finding themselves facing new challenges since the implementation of KanCare, or the continuation of other problems.

### *Quality of Care under KanCare*

When I asked providers about quality of care, the consensus was that KanCare is little more than the apparatus by which claims are resolved and reimbursements are distributed, and they saw no way that KanCare actually impacted the quality care. Eric exclaimed as he threw up his hands, “I don't see how it does anything for quality of care!” Other providers were not as animated about care quality effects as Eric, but in general, they shared his sentiment. Kristen said she did not see how one could even measure quality of care with all the changes she sees “every few months.” They saw no way that KanCare changed how they provided care to their patients or communities other than new obstacles to providing care. As such, three subthemes emerged on the issue of care quality under KanCare. For some providers, an obstacle was losing local resources. Others identified access issues. For most, the new pre-authorization and claims processes caused trouble.

### *Loss of the Local*

Under KanCare, there are three ways that providers have experienced what I call a ‘loss of the local.’ The first is how KanCare is dismantling long-held networks of provider relations between Kansas and Missouri. The second is a disconnect of case management from local

resources and networks. The third is a loss of the personal connections providers had with local case managers.

Rachael was frustrated. Her community health center has been working with health providers across the border in Missouri for years to provide high quality care at the local level. Her patients will have to “go long distances for possibly lesser quality care,” such as to Kansas City a couple of hundred miles north, a problem when mobility is limited, or the individual does not have the money to travel far.

Some providers felt that KanCare was not going to do anything more to coordinate care than what other local non-profit organizations had already been doing. In fact, the health homes KanCare promised are yet to be implemented,<sup>128</sup> other than a pilot program for people with serious mental illness which was ended prematurely in January 2016.<sup>129</sup> The organization Kristen directs has been assisting consumers with disabilities on long term care waivers with their in-home personal care attendants. Her organization, along with a network of other grassroots organizations, has been more or less coordinating care for consumers at the local level for years. Under KanCare, this function is being taken away from her organization and others like it. There is a “disconnect from the local,” Kristen said. For example, when her organization was doing case management (which they still do to some extent despite what MCOs do), her payroll and care coordinator staff sat next to each other. They could “overhear each other and work together” effectively. This was efficient from her perspective. Now, there is “no communication,” “no way to tell [her organization] that a consumer went to the hospital.” This is

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<sup>128</sup> Shields, Mike. 2014. “Surprise Halt to Health Homes Program Dismays Medicaid Providers.” *KHI News Service*. Retrieved February 15, 2016 (<http://www.khi.org/news/article/surprise-halt-health-homes-program-dismays-medicaid>).

<sup>129</sup> Hart, Megan. 2016. “Advocates Wonder Whether Health Homes had Enough Time.” *KHI News Service*. Retrieved February 15, 2016 (<http://www.khi.org/news/article/advocates-wonder-whether-health-homes-had-enough-time>).

information they need to know to help ensure their patients receive the proper in-home care at the right time. It is this loss of local connection that worried her.

The loss of a personal connection they had under the old system was also a problem for providers. It is “just phone calls, not forming a relationship,” Eric said. Moreover, as Gayle explained,

We often times talk to one person on Monday and they tell you one thing, and then you talk to another person on Wednesday and they tell you the complete opposite. I think that the missing link to me seems to be is having a customer service type thing - one contact person for a region when we have issue to get to the bottom of it. That would be so helpful. We used to have that when the state did Medicaid. We had a person we could call, and she would tell us how to fix it was great, because we knew who to call. And we knew we could trust the information we got. But now it's more confusing.

Consumers who had been working with the same case manager for years are now working with someone else, more often than not, at a call center outside Kansas that does not understand the local resources and needs. Some case managers left their jobs with the state or another organization to go to work for one of the MCOs, as some providers told me. The law says consumers are entitled to keep their case managers<sup>130</sup>, which I found interesting and did not know about before I interviewed consumers; otherwise, I would have asked about that. Yet, nothing in the law kept case managers from quitting their jobs, as has been the case according to providers. With their leaving is a loss of “institutional knowledge,” as Kristen put it, which has been the bedrock of successful case management in the past. Under KanCare, a consumer may now be one of 80 to 150 cases a single case manager has on her plate, depending on the MCO, and a case manager that does not possess the institutional knowledge consumers have been able

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<sup>130</sup> “Facts on I/DD Waiver Long-Term Services Incorporation into KanCare.” Kansas Department of Disability and Aging Services. ([https://21b8qg.bn1304.livefilestore.com/y3mFe6KKhqxsLheiSWq6FvduyrJgTEfFpIgqeRAWVcxIFMcPraPKUQc2DYi0VmNkBKQaFR0clXFLKsY\\_mw2BeJRdNCxtMyIL-JoiBrohwVuS\\_dG5G6X4K9ABycJKmRW8Dvo/Sec\\_Sullivans\\_Facts\\_on\\_IDD\\_Waiver\\_Incorporation\\_into\\_KanCare.pdf?psid=1](https://21b8qg.bn1304.livefilestore.com/y3mFe6KKhqxsLheiSWq6FvduyrJgTEfFpIgqeRAWVcxIFMcPraPKUQc2DYi0VmNkBKQaFR0clXFLKsY_mw2BeJRdNCxtMyIL-JoiBrohwVuS_dG5G6X4K9ABycJKmRW8Dvo/Sec_Sullivans_Facts_on_IDD_Waiver_Incorporation_into_KanCare.pdf?psid=1)).

to take for granted. “It takes time to train new staff,” time that providers, and especially consumers, do not have to waste.

### *Health Care Access*

Another barrier some providers talked about was access. Some encountered a continuity of care problem immediately after implementation in 2013, with consumers being directed to different clinics by mistake. As providers explained, the computer system that automatically assigned consumers to one of the three MCOs failed to include community health centers in its calculations. Lauren said that because of this oversight, she had to turn away consumers her clinic could normally serve. “Initially Federally qualified health centers were left out by MCOs when assigning patients, and it took a month to figure this out. This was financially damaging to my clinic. We had to have a sign in the lobby that said if you’re covered by KanCare, we can’t see you.” Eric said his clinic had a similar experience. Fortunately this problem was corrected, but it left some providers I met uncertain that KanCare was going to work as planned.

As the research literature suggests, managed care does not necessarily improve health care access. It did not seem from these providers’ perspectives that more doctors would begin accepting Medicaid under KanCare. “KanCare didn’t create more doctors,” Rachael observed. Not only that, but KanCare did not incentivize more providers to accept Medicaid, according to Eric. I asked him why more doctors do not accept Medicaid, and he offered a few explanations. First of all, “they don’t have to” accept it by law. “They perceive no need for it.” Second, there is perhaps a “cultural bias” in not wanting “*those people* in their offices,” he said sardonically. Research has shown that racial minorities do experience discrimination in health care settings. Eric talked about the issue of cultural competency as it related to his own experience with his community health center.

The Federally Qualified Health Center that Eric manages serves a large Hispanic community, which is also an underserved area. I visited the clinic one morning and observed that at least half of the people in the waiting area were (based on appearances) racial minorities. The two receptionists at the front desk were speaking Spanish to some of the patients. I do not recall seeing a man or woman alone but recall seeing couples, or couples with small children. Eric explained that a woman cannot be alone with a doctor in some cultures, and that for some of his patients, their children have to be present to translate, as the child speaks English while the parent does not. To what extent complex, or maybe even embarrassing, health issues can be adequately communicated through a child to their parent is of concern. “Doctors just don’t know what to do” in those situations, he said, and it might be a reason why some private providers in the area do not accept Medicaid/KanCare. “I just think they are racist and don’t want to deal with it,” he said, or at the least they do not have the “cultural tools” to deal with diversity. The issue of cultural competency and doctor-patient communication are well-documented problems in the research literature (Perloff, Bonder, Ray, Ray and Siminoff 2006; Holmes 2012; Baker and Beagan 2014). Eric’s clinic is the only provider of care to many Medicaid consumers in the suburban county where the clinic resides, especially for recent South and Central American immigrants and their families. If consumers do not go there, then they have few alternatives, he said. Whether providers are culturally incompetent or prejudiced is a matter of speculation, but the problems he raised are important to consider.

#### *Pre-authorizations and Claims*

Another component of quality of care is actually providing the care consumers need. However, two problems most providers I met reported consistently were delayed pre-authorizations and denied claims. Rachael told me her “horror story.”



We had to order an MRI for a lady who came in dizzy, had a headache, and could have been a serious brain problem. The authorization took one week, and then it was denied. The MCO suggested a CT scan. The results suggested the need for an MRI, but then denied again. Radiology is contracted out as are the other pre-authorizations. Typically the practice has been a doctor [with the pre-authorization company contracted by the MCO] contacts the doctor. But we were told this was not going to be the practice in Kansas. The next day, that changed.

Under KanCare, providers now must receive pre-authorization from MCOs before they can even provide care covered by Medicaid. Nancy, an owner of a physical therapy clinic that serves Medicaid patients, typically children, echoed Rachael's concern. The pre-authorizations are a "barrier to care," with "redundant paperwork" that is "time consuming." Each MCO, providers said, had their own procedures to process authorizations. Their systems were "inconsistent." For instance, Brenda, an authorizations specialist with a non-profit provider of in-home long-term support services, said her organization had to do a lot of follow ups with Sunflower, one of the three MCOs. "We were asked to call in pre-authorizations, but that was not true. They said to fax them, but they would be lost. We could use their website, but it was not working." It would take up to two weeks to receive authorizations from the MCOs for acute care, time that is critical for patients' care. "This inhibits care after hospital care." MCOs would not really explain authorizations, what was needed and so forth. As Brenda said, "it is more work to provide care even though we have the same number of patients."

The other issue is claims. Providers told me that MCOs approve or deny claims based on decisions made by their resident health care professionals or from a company they contract with that specializes in health insurance claims, in particular the company Cenpatenco. MCOs use 'evidence-based medicine,' or the practice of determining treatment based on the most current research findings. This practice made sense to me. But as I learned, it becomes a problem when the evidence-based treatment does not work for a specific patient. Four different providers gave

examples of patients that were denied treatment because the MCO did not agree with the provider on the course of treatment. The MCOs were occasionally denying claims for treatments that had been working for their patients, because the treatment did not align with their evidence-based medicine decision-making scheme. Yet, the providers said that they know their patients, their histories and idiosyncrasies better than the MCOs and know what treatments work for them. One example was a patient that had a history of responding better to the name brand form of a particular drug than to the generic version; however, the patient's MCO denied the claim for the name brand but approved the generic. The reason could also be about cost, but regardless of the MCO's reasoning, providers believe they should be able to treat their patients as they deem necessary.

At the heart of this conflict, it seems, was a power struggle between providers and MCOs over who determines the needs of patients. It is the cultural hegemony of health care providers and specific knowledge about their patients on the one hand, and the technical expertise of MCOs on the other in conflict. Provider organizations have conflicting interests with the state and MCOs. Providers need to be paid for their services, but the state and MCOs focus on controlling costs. Somewhere lost in this mix, I would suggest, is how consumers feel about their needs and what they think might be in their best interest. As I mentioned in the previous chapter, this is a key point made by health care consumer advocates. Providers also tended to agree. Eric felt that KanCare was not a “patient-centered” model. It was just about reducing costs.

#### *Controlling Cost Growth or Cost Shifting?*

Providers understood that KanCare is supposed to reduce the cost growth of Medicaid in Kansas, as policymakers claimed. If there are improvements to health outcomes and the quality

of care, they could see how KanCare might produce cost savings. Gayle's thoughts on KanCare's purported cost savings symbolizes what the providers I met tended to feel about the reform.

From my understanding KanCare was enacted to save the state money. I think I'm probably just repeating what I have heard. That it is going to provide better health outcomes and save the state a lot of money in the long term. I don't know if that's what's going to really happen, but [...] I just figured they're going to do what they're going to do, and we are just going to have to learn to work within whatever they decide to implement.

Providers saw the changes as inevitable and resigned themselves to working with the new system. What working with the new system to control costs meant was more work for them.

KanCare was to reduce cost growth by requiring all consumers to be enrolled in managed care, something critics did not necessarily support due to their skepticism that it actually produces cost savings or was even appropriate for certain groups. Rachael echoed concerns of advocates when she said that she was critical of policymakers framing KanCare as “managed care” and how that would cut costs.

I think they truly believe that managed care will reduce costs. For me, managed care is case managed care<sup>131</sup> for the most expensive care and manage that care. But there is no case management in KanCare. I think the governor is well-intentioned, but there are unintended consequences.

Providers had a different understanding of what constituted ‘managing care.’ Eric agreed. There is “not management of care.” MCOs are “just payers,” he said. Providers did not see how MCOs would manage consumers’ care beyond just paying their medical bills. In fact, they did not understand how KanCare was going to do anything about reducing costs, except to perhaps shift costs to someone else. This is one of the unintended consequences of the reform Rachael was talking about.

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<sup>131</sup> She means targeted case management, which KanCare was supposed to introduce but had not yet done so to a great extent by the time of my research.

Rachael, like others, was deeply concerned that cost savings were coming at the expense of her patients. “They had to reduce costs, but... people are not getting what they need.” Other unintended consequences are denied claims and delayed pre-authorizations. Denied claims, though they would be often times later approved, and delayed authorizations, which eventually usually went through, had the unintended outcome of delaying costs of providing care, but at the expense of the consumer in the form of barriers to care. While this “cost” is not easily measurable, it is worth considering when thinking about what constitutes “cost savings.”

One big fear expressed by providers was that consumers might experience a reduction in services, which is one way costs are shifted from the state. Policymakers insisted that cost savings would not come at the expense of providing care. However, Kristen argued that this might not be the case. She presented evidence to the KanCare legislative oversight committee that suggests in-home care attendants billed fewer hours as measured by the total administrative costs reported over the course of a year. Between 2014 and 2015, there was a “drop in hours for attendants, in other words, cuts in services.” The number of consumers her organization serves has not changed since 2001, so the only change she can point to that might cause a decline in costs reported is KanCare. “I would expect a 3-4% fluctuation from year to year,” but attendants “billed 27 percent less in 2014 than in 2013.” Because this is the experience of only one provider, I had to remain skeptical. However, it raises a question. Would an independent evaluation of KanCare that looked closely at the administrative costs reported for in-home care attendant hours billed see if there are any significant changes after 2013, which might indicate cuts in consumers’ plans of care? Meaning, did consumers have fewer hours approved by MCOs to hire an in-home care attendant, but their health did not change? I would think that multiple

years' worth of data would be required to note any unusual trends. Still, her experience should be taken seriously.

The problem of delayed or incorrect reimbursements kept coming up in the interviews, except for Gayle who said she has not had issues and thinks the system is better for her clinic. Nevertheless, while some providers were sometimes worried about reimbursement rates being reduced under KanCare to cut costs, which did not happen until 2016, one reality most experienced was a delay in reimbursements, at least initially. Delayed reimbursement was a problem that began immediately after KanCare was implemented in 2013. For community health centers and non-profits, any delays were problematic. For her in-home care organization, as Brenda explained, the United Way helped to offset its costs when it did not receive timely reimbursements from the MCOs. In other words, an organization that does not even directly provide care to consumers indirectly picked up some of the costs of providing care. For community health centers, though, they did not often have such supports. Delays just meant eating the cost now and paying for them later – difficult when budgets are limited. It is “willful neglect” on the part of MCOs to delay payments for services rendered to his patients, Eric felt, though he thought MCOs were getting better.

Along with delayed payments were incorrect payments. While this sounds like a normal problem of human error, providers claimed this was a bigger problem under the new system. For instance, Lauren talked about how her center was “getting paid wrong.” This created a “problem for federal reporting.” Medicaid providers must report payments properly to ensure there is no fraudulent activity. Incorrect reporting could be grounds for an investigation for Medicaid fraud, which just makes things even more costly for providers.

The problems these providers claimed to experience, including delayed or incorrect payments, denied claims and pre-authorizations, as Lauren stated, were having a “financial impact,” because of the “staff time and money spent just fixing problems.” Providers had to “put forth more effort to get information, training and to get results.” Kristen had to hire a CPA to help with KanCare reporting, and she has to do “a lot of extra work to ensure consumers are getting their needs met.” Rachael said she had to hire new staff just to keep up with the administrative end of providing care. It is a “cost shifting” she said. In New Mexico, cost shifting to providers is exactly what researchers found. The focus on personal responsibility ended up being a shift in cost to providers with helping consumer navigate the complexities of the new managed care plans (Lamphere 2005: 13). Provider workloads increased due to more red tape and constantly changing rules and procedures, something providers I interviewed mentioned as well. This makes me wonder if cost shifting is a structural problem with Medicaid managed care itself, and not necessarily an issue of poor planning on the part of policymakers and the MCOs. Regardless, what these providers described was the process of devolution: the state shifting costs onto the MCOs who then passed along the costs to providers and their sources of support.

When I followed up with some of the providers in 2015, they indicated that the reimbursement problem had improved. They are “better,” more “consistent,” and are being “paid in a timely manner,” Eric said. “I feel pretty good about it.” Brenda stated that two of the MCOs, United HealthCare and Amerigroup, were better in general. A billing specialist in her organization Brenda referred me to, Heather, confirmed. “I think things have improved as far as reimbursements. We don’t seem to have any problems getting paid.” There are media reports of

providers still dealing with reimbursement issues, though. As far as the providers I interviewed are concerned, their reimbursement experiences were better.

In sum, the views of the providers I met ranged from the overly critical, seeing it as detrimental to consumers, to something more practical-oriented, understanding that there is a change that was coming no matter what and just to deal with it, though it might not be the best idea. They had mixed feelings on privatization. Eric thought that “the private sector has no business in Medicaid,” but others like Nancy thought there should be private-public partnerships, and other did not raise the issue at all. What concerned providers more was the increased workload they experienced. They tended to feel that, perhaps with some exceptions, they were having to do more work to make KanCare a success. In some cases, such as with oral health, the work of care fell on the consumer, because, despite the rhetoric, the new services provided by KanCare was effectively meaningless. They understood that reform is not easy and that a major change like KanCare would come with some bumps in the road, initially, but perhaps if they had been more included in the development of the reform as advocates suggested, then some of the problems providers experienced would likely to have not been as bad. In all, the relative consensus among the providers I talked to was that change was necessary, but just perhaps not in the form it took with KanCare. Nevertheless, it was the system they had, and they had to make it work despite its limitations as they saw them. In the next section, I will discuss some of the ways that providers helped make KanCare work.

#### *Making It Work: Provider Strategies after Reform*

Some initial problems have improved, such as prior authorizations and claims, but delayed reimbursements are still an issue. These early experiences with implementation colored providers’ perceptions of KanCare. It is surprising, since with any new program there are likely

to be bumps initially and with them frustrations, but what was the most interesting is that the troubles did not just simply resolve themselves. Based on what providers said, problems were resolved partly through the day to day struggles of providers to educate MCOs on Medicaid and Medicare issues, resolve claims, navigate the red tape of each MCO, and ensure consumers received the care they needed. “We take it upon ourselves” to provide care to our patients “no matter what the MCO does.” That is, providers did what they had to do to make KanCare work for them and for their patients despite the systemic problems they faced. “Providers are taking responsibility, but not the MCOs,” Brenda explained as she questioned the extent to which the KanCare MCOs were trying to resolve problems they experienced. Her sentiment was echoed by other providers who, no matter what their troubles, did not just sit back, complain, and wait for the system to fix itself. These providers went beyond simply providing care in the technical sense or, for those working in an administrative capacity, just ‘doing their job.’ Each of these individuals discussed the different ways that they go beyond their expected roles to help their patients. They were, as Brenda put it, “working hard for just a small amount,” but they felt an obligation to do right by their patients.

Work transfer resulted in a range of strategies providers employed to smooth the edges of a rough implementation process. Strategies ranged from adding additional staff, increasing person hours to resolve problems, educating MCO staff, calling MCO leadership directly, advocating publicly for consumers, ‘fudging the numbers,’ and providing care without all necessary obligations met to the MCOs. Some of these strategies can be thought of as pragmatic, others, desperation. One example was particularly telling of how providers went out of their way to make KanCare work.



To resolve her “horror story,” Rachael, as the director of her community health center, dealt with the problem herself. “I had to call the president of Amerigroup to get something.” Resolving authorization issues is typically done by office staff, and if there are problems, each MCO has a procedure to address provider complaint. In this case, though, Rachael had to circumvent the processes, after they had failed to produce results. “It’s been stressful. Difficult. We have to intervene at the state level and go to the top.” Escalating an issue to the top executive of the MCO is more than what I expected to hear.

For care that they have been providing to some of their patients for years, some providers encountered denials of claims that had never been denied before, as Nancy explained. Patients who needed 15 to 20 physical therapy treatments would only be granted 10. They would constantly fight the MCO to be allowed to deliver the care they felt their patient needed and deserved, care that worked for that specific patient. “I had a nurse spend 20 hours in a week just on one claim.” Provider organizations would make repeated calls, escalate to higher levels in the MCOs, and expend far more person hours just challenging one claim than what they would expect to spend on multiple claims. Eventually, the claims would be resolved, generally, in favor of the patient.

I do not suggest that these sorts of strategies are commonplace or normal, because of the unrepresentative sample of providers in this study, but what can be learned from these particular instances of providers going the extra mile is that the implementation of health policy is a multilayer process in which policymakers enact the law and create the structure of the program, and then it is up to people in the state agencies, MCO offices, and health care settings to actually bring the policy to life. In other words, providers, in this instance, take what is on paper and apply it to real world situations of imperfect information, poorly trained MCO staff, inefficient

bureaucratic processes, inconsistent computer systems, confusing procedures, miscommunication, and power struggles between providers and the MCOs. In the process, providers made KanCare work for their patients.

Interviews revealed how providers went out of their way to help their patients. It may seem intuitive, but it is not the physicians I spoke with but clinic directors and owners and individuals working in billing and administration. The “back office” side of KanCare was enlightening, in that I learned a lot about the business side of doing care and how that act of care comes with the compassion and empathy I would have expected from a physician. Of course, most of these providers had a financial incentive to make KanCare work. Safety net providers and community health centers nationally receive over one-third of their revenue from Medicaid (Kaiser Family Foundation 2013:10) and are key providers in underserved areas with high concentrations of poverty (2013: 22). But it was more than that to them. Those on the administrative side of care provision exhibited a commitment to their patients that went beyond simply gaining revenue for their organizations through Medicaid. Informing the extra work that some of these providers took on was a public mission ethos and patient advocacy.

#### *A Public Mission Ethos*

These providers expressed a strong commitment to serving the health needs of the community. They understood there was a need in their communities and they sought to fulfill that need, whether it was through being a provider of physical therapy and oral care to children living in low income families, in-home care to persons with disabilities, or primary care to underserved communities. These providers wanted Kansas to expand Medicaid under the Affordable Care Act, not just because it would bring them more business so to speak, but because they felt it was the right thing to do for the community to improve access to care.

Providers wanted to make KanCare work, and if it did, then why not expand it to more of the people of Kansas was the general sentiment they conveyed. They saw care as a public concern and not just a private trouble.

Providers were initially concerned that KanCare conflicted with their commitment to community health and their mission to provide care was in jeopardy. They thought that the state did not share their commitment to help underserved communities, though that feeling seemed to have subsided somewhat over time based on the follow up interviews. Serving publics can mean taking on a certain level of risk, as some patients may not be able to pay their bills or may not follow through on treatments. In some areas, the community health clinic is often the only provider that accepts Medicaid or helps low income families and the uninsured. Dentists will not often accept Medicaid because it pays 40 cents on the dollar in Kansas. Clinics provide care to these groups knowing they are not going to make money, but surplus revenue is not their motivation. Perhaps they felt a calling to provide care. “We go out into the community...to schools...to educate the public on health,” Gayle explained. “Private providers do not have that same mission.” It is not that private doctors or dentists do not care; “it is just not what they do,” it is not their primary impetus for providing care. Health was a public good from the community health provider perspective. As a public good, providers felt they should be able to weigh in on the evolution of KanCare, and perhaps even its initial design. Patient advocacy was a second way providers helped make KanCare work.

### *Patient Advocacy*

For those providers who did try to make their voice heard, they found doing so came with risk. Kristen talked about how consumer advocacy is considered a care service under state and federal contracts. On behalf of her patients, she wrote a 30 page appeals document to the state to

resolve problems. However, she was told by state officials that she “cannot be with the consumer in the appeals process.” She cannot “lobby,” because her organization received Medicaid funds. Only the professional associations, such as Kansas Advocates for the Medically Underserved, a provider advocacy group, can lobby. The state redefined what “lobby” meant in its contracts to providers, making advocacy more or less synonymous with lobbying. The language in state contracts with providers reads: “No part of the funds provided through this contract shall be used to influence or attempt to influence an officer or employee of any State of Kansas agency or a member of the Legislature regarding any pending legislation or the awarding, extension, continuation, renewal, amendment or modification of any government contract, grant, loan, or cooperative agreement.”<sup>132</sup> Indeed, after writing the appeals, she told me that she received a call from Sec. Shawn Sullivan (at that time the head of KDADS) saying that she could not advocate on behalf of her patients, as that was considered lobbying. Nancy told me of another health care provider who encountered the same experience. A news article in 2012 speaks of this issue, as well, and the concerns non-profit providers had over this language in the contracts that they felt might limit their ability to advocate for consumers.<sup>133</sup> The feeling some providers expressed in light of this issue was concern that their voices cannot be heard, and that they are limited to what they can do to ensure their patients receive the care they need.

In sum, health providers felt like they had to do more work just to make KanCare a success for their patients. For providers, devolution in health care entails more administrative work, strategies to get through new red tape, educating MCOs, and advocating for their patients.

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<sup>132</sup> “DA-146a (Rev 06-12) Contractual Provisions Attachment.” Kansas Department of Administration. Retrieved February 16, 2016 (<https://admin.ks.gov/docs/default-source/Chief-Counsel/da-146a---contractual-provisions.pdf?sfvrsn=2>).

<sup>133</sup> McNamara, Don. 2012. “Kansas Non-Profits Hit with New State Contract Provisions.” *The Non-Profit Times*, July 2. Retrieved February 16, 2016 (<http://www.thenonprofitimes.com/news-articles/kansas-nonprofits-hit-with-new-state-contract-provisions/>).

To them, KanCare had its limits, especially for dental care, but providers wanted it to succeed, and they tried their best to make that happen. On the one hand, the increased effort was uninvited, but on the other hand, it was in line with their public mission sensibility. No matter what, they were going to make the system work for consumers. They did not like it, but it had to be done. I turn now to the work transfer experience of consumers.

### **Work Transfer under KanCare: The Consumer Experience**

For consumers, work transfer is not so straightforward. It is not necessarily evident to them, but in their stories, they do tell of their own struggles to provide for their care. Poverty was a complicating factor for their health, but their strategies to deal with constraints of poverty and dependency arguably helped them to mitigate stressors in their lives. Their stories challenge stereotypes of the poor and people receiving public assistance and illustrate how the personal responsibility narrative undergirding KanCare is out of step with their lived experiences. The work transfer consumers experienced was, in a sense, more of a discourse than a material process, in that policymakers are now telling consumers to do what they have already been doing all along but without effectively empowering them to do it. Policymakers want more personal responsibility, but these consumers' stories problematize that imperative. Each consumer, while their experiences and health issues were different, faced similar troubles of housing and poor quality social environment, constraints of income and work opportunities, and social isolation to a degree. I use stories of individuals that best highlight each theme.

Although the interviews were directed to their experiences under KanCare, consumers talked more about their health and the challenges they face in their lives in general, despite efforts to steer them back to the subject at hand. In the end, the fact these consumers opened up about their lives and what they deal with on a daily basis proved to be far more interesting and

valuable than just their opinions on Medicaid or health care, something not typically found in evaluation or attitudinal-type studies of Medicaid (e.g., Hall, Kurth, Chapman, and Shireman 2014). Their stories gave a sense of what it is like living with certain disadvantages. As I listened to them, what I heard were individuals who were at one time financially secure in their own right. They had college degrees, promising futures and careers, but then their health took a turn for the worse, and now they find themselves living with less than average health or a disability, and in some cases, severe illness, to the point that they are dependent on others for their wellbeing, despite their wishes. Their stories highlight the problem of health in the context of poverty.

### *Health in the Context of Poverty*

#### *Fundamental Causes Theory*

Link and Phelan (1995) argued that illness is, fundamentally, a product of social factors. Thus, a focus on proximate risk factors that presumably can be controlled at the individual level fails to adequately explain why some people do not have sufficient access to resources that help to avoid disease and their negative consequences in the first place and fail to explain the social patterning of disease. Fundamental causes can take the form of socioeconomic status, gender and race, stressful life events and circumstances, and stress-process variables like social support (1995: 81). Researchers have demonstrated the causal linkages between social factors and disease (Link and Phelan 1995; Link, Phelan and Trehenifar 2010), but they have not always considered the primacy of social conditions versus social selection, that is, the illness causes the context and not vice versa, in determining the causal direction between social factors and illness. Given the nature of the illness, the social selection explanation might be more apropos. For Medicaid consumers, some health problems might actually predate their low socioeconomic

status, which then ends up limiting their economic and social resources, thereby contributing to dependency on a system that affords them little opportunity for changing their circumstances.

For the consumers I interviewed, this was exactly the case.

Consumers engaged in different strategies to overcome their dependency and disadvantage, which complicates the social selection/social conditions dualism the fundamental causes thesis implies. They continue to be disadvantaged in terms of housing, income, and social support – social mechanisms that could mitigate some of the negative consequences of their health conditions thereby contributing to a somewhat better quality of life. Their stories that suggest the relationship between health and social conditions is a struggle in light of a program like KanCare, that could, but in ways does not, mitigate the negative relationship between illness and poverty. In other words, these consumers did the work of overcoming obstacles of poverty in areas where policy is insufficient, absent, or fails.

Three distinct themes related to health in the context of poverty emerged from the interviews. One, consumers discussed their living conditions: for some, their environment exacerbated their health issues and lowered their quality of life, for others, it compounded their experience of poverty, which had indirect impacts on their care. Two, they talked about their desire to work, or how they used to work but now are unable to do so though they want to be gainfully employed. Three, they described various levels of social isolation, in terms of their lack of family connections and immobility. Taken together, the three contextual factors illustrate different aspects of living in poverty. In some ways, their stories confirm the Link and Phelan theory, but in other ways, they challenge them. Moreover, these themes illustrate how the prevailing ideology in Kansas that emphasizes the necessity of work and self-sufficiency contradicts the realities of the poor who are disabled or ill.

### *Housing and Environment*

One unexpected theme that emerged from my conversations with consumers was the issue of environment: housing and neighborhood. Scholars have found relationships between health and social environment, such as the effect of friendliness of the local environment on self-rated health and social nuisances with obesity and poor self-rated health, which has implications for diabetes, heart disease and cancer (Poortinga 2006). It is not just the physical aspect of the environment inhibiting good health behaviors (e.g., exercise) that is at fault. Characteristics of the social environment can impact the susceptibility to stress or facilitate the exposure to stress (Turner 2010: 5), which is at the heart of the stress process model (Aneshensel 2005; 2009; Pearlin 1989). Noxious neighborhood characteristics, such as crime, drug use, garbage, and noise, act as chronic stressors that, in turn, negatively impact physical and mental health (Hill, Ross, and Angel 2005), in particular for those living in poverty and when intervening social supports and personal resources (e.g., empowerment, self-esteem) are weak. Quality housing that facilitates a good quality of life is limited for some KanCare consumers. Housing can be of poor quality, and the neighborhood can be stressful or even unsafe. Robert's story highlights this challenge.

I met with Robert in a cozy little library in his apartment complex, which was full of books, a few comfortable chairs, a computer, and decent lighting. It was quiet and relaxing, but smelled of old furniture, which nonetheless appealed to him. His living space had not always been like that. Robert lived in Topeka for a several years, but absolutely hated it. It was an environment that was not “intellectually stimulating,” as he put it. “The people there were not very interesting.” Intellectual stimulation was important for him, helped him thrive. Living there was also noisy and toxic to his health, and he had to be rushed to the emergency room several



times a month because of anxiety attacks. He had also gained a lot of weight and was very unhappy, which he felt exacerbated his diabetes symptoms. After working through a contact in another city, he was able to secure an apartment at a low income residential building in eastern Kansas, but it took him two long years. In comparison with how he thought of his neighbors in Topeka, “the people are interesting here.” Since moving to his new home, he no longer has to be rushed to the emergency room and that his overall health improved. In a matter of weeks, “my diabetes symptoms declined,” he said.

Research shows that there is a lower likelihood of mental illness in neighborhoods with a greater presence of stress-buffering mechanisms, specifically larger numbers of people living in each home and the number of churches (Stockdale, et al 2007). Social isolation, low social support, and crime tended to exacerbate health problems. For Robert, the main obstacle to acquiring a healthy living space was financial. His living conditions, like other consumers I interviewed, were a result of downward social mobility caused by their illness or disability. This left them unable to afford better housing. One study showed that “the average rent for a studio apartment in Kansas is 73 percent of the average Social Security Income (SSI) payment, making quality housing unaffordable for adults living with serious mental illness who rely on SSI.”<sup>134</sup> Nevertheless, Robert did the best he could to improve his health and reduce his unnecessary emergency room visits when he pushed to move from Topeka to his current home. He did not take the stresses of his social environment lying down. He also writes poetry now, which is therapeutic for him, and he talked about how he wished it could be published. Moreover, he enjoys chatting with his fellow residents. So now he has access to the kinds of stress-buffering mechanisms research shows helps mental illness.

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<sup>134</sup> National Alliance of Mental Illness. “State Statistics: Kansas.” Retrieved September 4, 2016 (<https://www2.nami.org/ContentManagement/ContentDisplay.cfm?ContentFileID=93494>).

Other consumers had similar experiences with quality housing, such as problems with insufficient lighting, being treated unkindly by maintenance people, drug addicts, and safety or at least their families did not feel safe visiting them. Sarah told me she was almost raped the first day she moved into the independent living facility where she currently resides. At the same time, Sarah said some residents of her independent living facility “donate things to the common area, such as pillows from a new couch, plants, microwave to try to make it homey here. Most are fairly well-educated here.” While there were some positive experiences she could speak to, she feared of drugs and crime there. It is hard for her to feel free and safe when living is a high-risk environment, a stressor the ideology of self-sufficiency and personal responsibility fails to consider. As such, place has an impact on a person's quality of life, both negative and positive, but where consumers lived was not so much of a choice as it was a matter of circumstances largely out of their control due to lack of personal and social resources, resources that are often dependent on labor market participation and social integration.

#### *Labor Market Participation*

The second challenge consumers’ face that has implications for their health is labor market participation. This was another unexpected theme that emerged in the interviews, and is a key factor in understanding how social factors, particularly socioeconomic status, matter for health, as Link and Phelan (1995) explain. While all the consumers I met dealt with some aspect of not having access to sufficient economic resources, such as Brian being a student with no life savings or regular employment, the stories of Sarah and Denise exemplify this issue well.

I met Sara and Denise in their independent living facility in eastern Kansas. They are neighbors who have become friends in their time living there. They are both well-educated women who share common sentiments about American values, poverty, health, and the social

safety net. The interview was in a common area for the residents, and they each brought their pets, Sarah's therapy dog Chloe and Denise's cat Allie Cat. Denise was the consumer who had initially called me about an interview, and, unknown to me, had invited everyone at the facility to the interview, but only her and Sarah were there. I listened as they took turns telling me their stories.

Sarah has a master's degree in special education and taught primary school for 13 years. She was diagnosed with multiple sclerosis after a car accident in her early 20's.

I just didn't know why things that happened to me happened to me all those years. I was in a really bad car accident right before I started my master's work. I never completely recovered from the brain and spinal injuries. They [doctors] thought, 'oh you are just overweight' or 'you are not working out enough.' ... I woke up one morning, and I couldn't walk for a few days. So things like that happened for 7 years before they diagnosed me with multiple sclerosis ... I was 29 when I was diagnosed. It was like I had a bilateral stroke by the time they finally figured out what it was that I had.

Although she wants to work, "I cannot work a regular schedule." Sarah could not hold a job because of her unpredictable health. In response, she started her own small business to produce a small income, not too much so that she does not lose her benefits, and one that allows her a great deal of flexibility to work when she is able. She participates a networking group in Kansas City in an effort to make business contacts and potential clients.

Several years ago, Denise began to have a series of severe headaches and her health was failing. After multiple doctor visits, she was finally diagnosed with a large brain tumor on her frontal lobe. After the tumor was surgically removed, she was unable to hold, as she put it, a "normal" job due to her poor health. "They don't want to hire me, because they think I am too much of a risk." Even if she could get a decent paying job, she would lose her disability benefits and Medicaid. "If I make more than \$728 in 3 months, I will lose my benefits." All Denise

really wanted was a fair shake and to empower herself to do a little more in her life. Social security disability income was not sufficient, and she felt like she deserved more.

“The amount I get is not fair. I started working when I was 14 years old. No, no, no, this is not right. 'Well, you are receiving pretty much the average of Kansans.' I am like, I am not the average Kansan. You don't know all the dirty work I did. I was a good citizen. I only applied for unemployment one time in my life. I only got two payments out of that. So give me more to help me live better.

Sarah expressed similar sentiments, as did other consumers. They both value hard work and independence through gainful employment, but because of their health, they have not had sufficient opportunity. Business hiring and management practices and the social safety net are weighted against women like Sarah and Denise trying to pull herself up by her bootstraps. America's workplace culture is too inflexible for people with unpredictable health conditions. Poor health can lock people into stressful situations that take a further toll on their health. Kansas has welfare to work-type programs and programs that help people with disabilities find work, but as Sarah commented, they are not that effective.

It is almost impossible to get out of the situation we are in. The Working Healthy program does not work the way that it should. In fact, it should be there for people who are trying to stay employed, desperately stay employed. You cannot afford to employ me. My own brother is a superintendent of schools and says '[Sarah], I couldn't even hire you. Even though you are a great teacher, I couldn't afford to hire you, because the health care increase that would go on because you might get sick this year and you need to be in the hospital for a couple of months. I can't afford that. For part time places, they say I can't afford you, because are super overqualified. But I have problems, I have a lot of problems that make me sick in the mornings. So I can't leave to go to a job at 8 am or even 9 am. That's just not a possibility for me. There are no five days in a row that I can do the same thing.

Denise and Sarah both valued their extensive knowledge about social services and talked about how they would like to share that with others, but they just wished they could be paid for it. Unfortunately, there does not seem to be much of a market for information. What they know and the skills they possess are not sufficient for gainful employment given the obstacles they face.

More importantly, they wanted to help people, but did not see an avenue for doing so. They felt stuck.

Each of these consumers had jobs at one time but are now unable to work due to their health. Robert was as an aeronautical engineer for the federal government, but after a short time on the job, he developed a serious anxiety disorder and began having trouble working. “I got really, really sick and I couldn’t work after that. I wanted to work, but my anxiety was so bad, I couldn’t work.” Since the late 1980s, Robert has been on disability and Medicaid off and on. Largely because of his mental health, he is unable to hold a job, though he wishes he could work. Disease prevents Brian from working even though he wants to be self-reliant and have a career as a pharmacist. Like Robert, poor health put a damper on his career plans. Health conditions inhibit even the most well-intentioned and qualified people from labor market participation.

Recent research on the health impacts of employment status finds consistently that unemployment has a negative effect on objective and self-reported health (Béland, Birch, and Stoddart 2002; Giatti, Barreto, and Cesar 2010), and mental health (Scutella and Wooden 2008). More relevant to the consumers I interviewed who had been jobless for many years, there is evidence that the longer a person remains unemployed, the higher their risk of mortality (Garcy and Vågerö. 2012) and the more likely a person will suffer psychological distress (Daly and Delaney 2013). Also, relevant to those consumers with disabilities, research finds that unemployment increases rates of self-reported disability (O’Brien 2013). For Kansans eligible for Medicare and Medicaid, employment of any sort tends to have positive outcomes for health, including less smoking, better quality of life, and higher self-reported health (Hall, Kurth, and Hunt 2013). Interestingly, half of their survey respondents were employed, but nearly all less than 40 hours per week. Moreover, they found a relationship between being employed and

significantly lower Medicaid in-patient expenditures, and slightly lower out-patient expenditures, for those who are employed.

While consumers talked about the limitations they faced because of insufficient income, it was not simply the lack of income that concerned them. Rather, it was not being able to work. For these consumers, being able to work and make their own way was important. Some talked about the limits of their small Social Security Disability Income, but what they talked about more was wanting a job and the obstacles to gainful employment they encounter because of their disabilities. Persons with disabilities generally face many social and individual-level obstacles to labor market participation, such as lack of access to disability-related health services, and are thus less likely to work than those without a disability (Henry, Long-Bellil, Zhang, and Himmelstein 2011). For those who do work, some face a “glass cliff” in career advancement (Wilson-Kovacs, Ryan, Haslam, and Rabinovich 2008). Work does not always improve health outcomes. Evidence suggests that among the 35 percent of Americans with disabilities who do work<sup>135</sup>, those who have moderate to severe functional limitations still tend to report poor health, though non-workers are more likely to report poor health than workers (Jones and Crews 2013: 1484). Consumers indicated that their disabilities do not fit well with the rigid structures of work in most settings but felt that they would benefit financially from employment.

One of the objectives of the Kansas welfare regime is to “get people back to work.” They do have access to the Working Healthy program, which lets them keep their benefits, but they were not convinced it works for them. Based on what consumers told me, they would need flexible schedules, sufficient paid sick leave, or even the means to work from home, but most importantly, to not lose their Medicaid benefits immediately upon receiving higher incomes if

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<sup>135</sup> American Community Survey FactFinder. Retrieved January 15, 2016 ([http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_14\\_1YR\\_B18120&prodType=table](http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_14_1YR_B18120&prodType=table)).

they are to benefit fully from work, a fear some expressed. Even when there are work programs available, barriers still constrain consumers' labor force participation, whether the reason is related to their poor health or disability, or structural barriers that exclude people with functional limitations. Thus, the ideology of policymakers in Kansas is not in line with the lived experiences of the consumers I met and those in similar circumstances of poverty and disability.

Caregivers are impacted, too, but in different ways. While we talked at a university student union, Gary explained how he had to forego his new career to tend to his mother's affairs. "My brother and I had to move to Topeka and live in my mother's house so that I could be close by to take care of her. I had to put my career on hold for a while." When a caregiver has to exit the labor market, there is often no support for them, except for the Family and Medical Leave Act of 1993 which provides up to 12 weeks of unpaid leave for eligible workers. Though the move was temporary, it was still a setback for him. He made a sacrifice to provide care to his mother. In her case, Gary's mother had to rely on her sons to help her, who themselves had to make tough choices to be closer to her, and as a result, in their efforts to be responsible caregivers, they paid a price. It seems as if though one cannot do both: provide care and care for yourself without help. This was the very problem Michael's family ran into when he learned that he might be losing essential professional in-home care.

Because of his health, Michael and I spoke over the phone and over email. He is in a wheelchair and uses a breathing machine. He explained how he is no longer able to work because of his declining health. He was a journalist for a newspaper in Missouri, but he still writes as a health care advocate as he is able. With a condition that requires around the clock care, his wife and children do the best they can to help. His wife works full time to support the family and is the sole breadwinner.

Already, my children – strong, loving, independent and caring – have been forced to grow up way too fast. My 13-year-old son often teaches certified caregivers how to run my breathing machine, perform breathing treatments, inject insulin and do blood-sugar readings. And under direct supervision, my 9-year-old daughter has helped to inject insulin since she was four.

Without this help, his family would have difficulty taking care of him, his quality of life would decline, and he might lose his wife because of the strain of her being the sole breadwinner and a caregiver. He would lose any semblance of a 'normal' life, as he stated.

What Michael and Gary's stories illustrate is the limits of labor market participation for providing long-term care. People who are unable to work because of health may need someone to assist them, either a family member or a paid caregiver. That people must rely on markets for resources constrains access to long-term care support for people living in poverty. If a family member can help, then paying someone is not a issue. However, if the family member also has a job, the role conflict caused by earning a living and providing care can put further strains on filial relationships, such as in Michael's case with his wife potentially divorcing him if he ever lost his in-home care attendant services. This is an example of why paid caregivers are so important - a service covered by Medicaid. But when that service is not an option, or when the option is restricted, then an individual must rely on unpaid family caregivers if they are to remain in the home. Unfortunately, Gary's mother was no longer able to remain in her home, but Michael was.

Policymakers today prefer home and community based care than institutional care (Naylor, Kurtzman, Miller, Nadash, and Fitzgerald 2015: 537), namely because they think it costs less, though some research suggests there is little evidence to back such claims (Guo, Konetzka, and Manning 2015). Why might that be the case? Long-term services and supports, which includes nursing homes and home and community based services, constitute a significant portion of overall Medicaid spending nationally. For example, while “dual eligibles represent



just 15 percent of the Medicaid population[,] they accounted for 39 percent of Medicaid funding in 2011, the bulk of which (69%) supported [long term services and supports]” (Naylor, Kurtzman, Miller, Nadash, and Fitzgerald 2015: 533). That is, a small number of consumers accounted for a significant portion of Medicaid spending on institutional and home and community-based care. The problem is that while policymakers focus on home and community based care, there are huge waiting lists for these services that constrain the extent to which the more cost effective forms of care can actually reduce overall expenditures. The wait list for home and community based care is a problem in every state, including Kansas. Access to non-institutional care varies widely state to state, with over half a million people on the wait lists nationally in 2012 with an average wait time of two years (Naylor, Kurtzman, Miller, Nadash, and Fitzgerald 2015: 543). Recent research shows that increases in Medicaid home care spending can reduce nursing home utilization and annual Medicaid nursing home costs, which normally far exceed those of home-based services, but only modestly (Guo, Konetzka, and Manning 2015), and if consumers are actually moved into those services. Part of what keeps costs down is that home and community based care produces better health outcomes.

States can implement home and community based care programs through Medicaid, which, among other things, pay for habilitation training, respite care, employment, transportation, behavior management and other therapies, and home health aides. Home health aides help people like Michael with changing bandages and dressing wounds, and applying topical medications, as well as bathing, dressing, and grooming. If one is not covered by Medicaid, one must pay for these services out-of-pocket, which is expensive. As such, “[p]ublic demand and the 1999 *Olmstead* [v. *L.C.*] Supreme Court decision require that states expand alternative home and community based service programs (Kitchener, Ng, Miller, and Harrington

2005: 206). People have better health outcomes, less hospital visits, and improvements in “life satisfaction, social activity, social interaction, and family caregiver satisfaction” when they are able to remain in the home than when in nursing homes. However, even with the increased focus on home and community based care by policymakers, which can pay for a home health aide, unpaid family caregivers provide the majority of care while usually holding a full time job outside the home (Naylor, Kurtzman, Miller, Nadash, and Fitzgerald 2015: 544). As Michael and Gary's stories illustrate, this extra burden may place additional strains on caregivers. The broader implications for unpaid family caregivers deserves further investigation but is beyond the scope of this study due to too little data.

While these consumers dealt with not having access to sufficient economic resources, they were unusual in that they all have college degrees. Having a higher education than the typical Medicaid beneficiary problematizes the impact socioeconomic status has on health as one might expect based on the fundamental causes thesis. Their education could actually serve as a buffer for some of the problems they experience. Another one of those problems that consumers talked about was their social relationships.

### *Social Isolation*

The third theme that emerged from the interviews is social isolation. Social integration is important for good health, because when people lack quality social relationships, they experience worse health outcomes than those with better quality social ties (Umberson and Montez 2010). Research consistently shows a strong link between social ties and support and physical and mental health (Thoits 2011). Being well-integrated with significant others, similar others (2011: 154), and secondary groups buffer stressors that negatively affect health. These groups can provide social support through “emotional, informational, and instrumental assistance,” where

instrumental support involves “offering or supplying behavioral or material assistance with practical tasks or problems” (2011: 146). Whether friends, family, or neighbors, individuals can experience better health when they have access to these sources of support. An individual’s network of social ties help to mitigate health problems through being models of good health habits, monitoring, encouraging, or reminding the person to do what is best for their health (e.g., following a physician’s prescribed regimen, taking a shower), providing meaning in life, a sense of belonging, and guiding behavior, being a source of self-esteem and control over one’s life (2011: 147-50). Even the perception of having social support can be beneficial to health (2011: 150). However, most consumers I interviewed were going it alone. They had limited mobility. Most were single, with no intimate partner or children. Brian had a mother he saw from time to time. Gary’s mother had him and his brother. While I was unable to interview his mother for the study, I found Gary’s story important, because of the role that family members often play as caregiver and manager of financial or legal affairs for some consumers (i.e., informational and instrumental assistance). For Michael, his wife and children, in conjunction with in-home caregivers, helped him maintain a more or less normal life.

Others, though, felt that they had few people, if any, upon whom they could rely. “I have a sister, but she does not really help, and my parents just don’t understand,” Sarah explained. I asked what she meant by not understanding, and she said her family thinks she is just being lazy and not trying. They do not understand the nature of her illness. Similarly, after her first brain tumor surgery, Denise commented,

At that time, I did not have any family members who could take care of me. I was still needing ongoing physical therapy. The place they placed me was a nursing home in Olathe, which really broke my heart, because I was away from my community, my family, my friends. Going to Olathe to them was like going to Oklahoma. People don’t want to leave out to go visit. Plus they were still in denial that I was in that type of condition.

This was Denise's experience for the nine months she was in the nursing home. She also talked about experiencing “reverse ageism,” as she called it, with older residents always questioning why she was there and did not like her participating in social events. She felt alienated, because she was much younger than other residents. Having a network of family and friends is important for good health, and having no family around or living in places where they do not feel comfortable or welcome, as these two women do, can make dealing with health problems difficult.

Denise has a cat, and it was with us through most of the interview. At one point, the cat was digging around in a giant flower pot and to help Denise, who has significant swelling in her legs because of diabetes and finds it a bit hard to chase after the cat, I got up and went over to the cat and brought her back over to Denise. Animals can be great companions to people living alone. “She gives me more accountability, I can tell you that. That's one thing an animal will do.” But pets do not make up for the absence of family and social supports. Going it alone can be difficult when one's resources are very limited and are limited by their poor health, as these women explained.

Though I did not ask about it directly, consumers talked about how family, or the lack thereof in many cases, makes a difference in their lives. For instance, Brian said that being unmarried, having no children, and not being responsible for anyone “makes it easier.” It also

[m]akes it harder in a lot of ways. Because you don't have anybody to help you go through paperwork. You've got to ask for favors, if you have to be driven some place. You have to call up people and coordinate, which I try to do myself. With all my surgeries, I always drive myself to chemo. So I think I have only gotten four or five rides. I do all the rest of the driving myself. I don't want to inconvenience anybody. It's funny. When I go in for chemo, I see other people come in with three or four people with them to offer support, and I'm just there by myself. So it does feel a little awkward sometimes.

So while being alone made him feel less of a burden to others, having others around for emotional and social support would improve his quality of life, he felt.

Robert felt that family can help. “If you have family, you can bear the system. You feel somewhat secure. But right now, my mother is deceased and I don’t get along with my brother. A feeling of aloneness. You are dependent on unfriendly people. Not everybody is friendly to being depended upon.” He later went on to say that “it is really hard being totally alone and being expected to function.” Being separated from a social network or family left him feeling insecure, left out, and no one to which he could turn for emotional support.

In conjunction with lack of social supports, for some persons living in poverty or with a serious illness or disability, getting from one place to another can be taxing and complicated. The logistics of setting up an appointment days in advance, as KanCare consumers are required to do, or just to take a walk for exercise, let alone for a last minute doctor's appointment, is not something persons without disabilities or those who do not live in unsafe communities, as do many of the poor, do not have to always consider. If your destination is not a doctor's office or your home, then you risk not being able to find transportation to where you want to go, as a gentleman with a disability at one of the public meetings I attended explained.

Mobility is a problem for the consumers I interviewed, not just because of physical disability but also because of their isolation. While many Americans can often rely on friends and family to get them where they want to go (i.e., instrumental support), or pay for a taxi service, people who live in more or less isolation and who are of limited means, and who have a disability, have few options. Some consumers rely on transportation services paid for by KanCare, but there are limitations to the services. “You must be on time and cannot be late, or they will not wait for you and you will miss your appointment. If you miss a doctor's visit, you

then risk losing your benefits.” Denise said there would be some sort of miscommunication between her and the transportation company resulting in her missing her scheduled bus and not being able to get to her doctor. To people with unpredictable health conditions like Denise, the system can seem punitive.

Sarah and Agnes both own a minivan. For Agnes, driving can be painful. Sarah is concerned that when she drives she could have an accident. She has her medical assistance dog Chloe with her at all times to make sure she does not pass out when driving due to her very unpredictable high blood pressure. The dog can sense when her blood pressure is about to skyrocket and can alert her so that she can pull over and stop in time. But getting around can be troublesome for her. She does drive but has to be very careful. She has the potential to pass out while driving, and the dog is trained to alert her to when she is having symptoms. Nevertheless, her mobility is limited. Mobility issues not only affect her quality of life and health care access, but it also affects her full participation in society. If she could rely on her family more, she would not have to worry so much about the fact that she needs to replace a part in her minivan that she cannot afford. So it just sits in the parking lot and she is stuck where she is

Indeed, the transportation issues consumers discussed echo the issues respondents in a recent survey of KanCare consumers who are on the Medicaid Buy-In program. Hall, Kurth, Chapman, and Shireman (2014: 4) found in the qualitative portion of their survey, respondents mentioned transportation troubles under KanCare. For example,

“Someone comes from out-of-state, no local provider, and I don’t know these people and they don’t treat me well or properly. Before, you knew the person, they were local and usually the same person each time.” “I have transportation up to appointments in Kansas City and they [MCO] provide it. But, sometimes I have two appointments and they won’t wait. So, I have to get a hotel and they come back the next day. Very expensive!” “My doctor’s office changed my appointment time, but the MCO won’t change the pickup time because it is not three days’ notice.” “Three days’ notice is hard to give sometimes.”

These are some the same complaints Denise had about her transportation service: that they are out of-state (based in St. Louis, she said), inflexible, and will make her wait for long periods of time. She told me about her struggles to make it to her doctor's appointments in face of difficulties with her transportation service. She would have to be ready for her appointment at least 90 minutes in advance so that she can catch the van sent by her transportation service. Assuming the van had only a few short stops, she should make her appointment in time. If she missed her appointment, she could be penalized and have to pay for it out of pocket. Additionally, if she missed her ride, she would not be able to make it to her appointment, and not only would she have to pay the cost of the doctor visit, she could incur a penalty from the transportation service and possibly lose her transportation benefit. Needless to say, the service is not convenient. She talked about having to wait for several hours in the early morning after being taken to the emergency room. Because she had to wait, she could not take her pain medication yet and could not go to sleep like she needed.

Like the consumers I interviewed, the respondents in Hall, Kurth, Chapman, and Shireman brought up the transportation issue unprompted. Could the issues they raised be because consumers are essentially indirectly 'outsourcing' their instrumental support mechanisms via KanCare, stress buffering mechanisms to which people not living in poverty have more ready access? This is an issue that warrants more study, not just in terms of consumer satisfaction issues, and the like, but in terms of how consumers must deal with their social isolation and the obstacles they encounter, especially considering how important social connectedness is to health.

Social connectedness has physical and mental health benefits. In their study of the relationship between social interactions and health, Fiorillo and Sabatini found "that, in addition

to the quantity of interactions, it is their quality – as measured by subjective satisfaction derived from relationships with friends – that works as the best predictor of self-reported health” (2011: 1644). A lack of connectedness, though, can be detrimental to health. Among older Americans, social isolation, in terms of restricted “independent life-pace” and inadequate transportation, increases nutritional risk, especially for Black women, as do lower income and less social support (Locher, et al 2005). Social isolation also contributes to poor mental health (Stockdale, et al 2007), which in Robert's case, for instance, feeling isolated in Topeka did not help his health at all.

Long-term illness and disability can strain family relations, leaving consumers potentially estranged from their families, physically distant and largely absent in their lives, or leaving people with no family at all. These gaps in meaningful relationships left consumers with little or no social support, no one to share troubles or feelings, and no one to help when the going got tough, with some exceptions. Brian has his mother, but he valued his independence too much and never wanted to bother anyone. Robert has a little community of like-minded people he can talk with at his apartment complex. Denise and Sarah’s friendship demonstrates that otherwise isolated individuals sometimes find one another and establish a bond grounded in shared experiences of illness and poverty. Michael does have family, a wife and two children, but without KanCare, those close filial relationships could be replaced by institutional care. No matter the specifics of their family situations, they all challenge a traditional family model in which social supports are readily available and that those supports are not strained, supports that are assumed to exist in the ideology of self-sufficiency. Part of being independent is having sufficient resources upon which one can consistently rely, and without those resources, being independent is a challenge, as consumers’ stories suggest. Thus, they had to do extra work to



make up for their lack of resources on top of the work they did just to maintain their health. In the next section, I discuss three kinds of strategies consumers employed to take responsibility for their welfare.

### *Strategies of Individual Responsibility*

This section explores how consumers dealt with their needs *despite* the context of constraint and exclusion as described above. In 2013, Kansas enacted KanCare to reduce costs of Medicaid, improve health outcomes of consumers and improve the quality of their care. Under KanCare, the state expects consumers to be more accountable for their health and healthcare. To accomplish this, the new program provided incentives for healthy behaviors, added free services intended to improve prevention, reduced the cost of prescription drugs to consumers, and introduced better care coordination to ensure consumers received “the right care at the right time” and thereby reduce the use of costly emergency room care. The idea is to make KanCare consumer more personally responsible.

The problem that consumers' stories suggest is that they are already being responsible people. The ways that consumers were being responsible people, that is, taking action to serve their interests, can be thought of as strategies. I use the word strategy, because their actions were not just gut responses to circumstances. They thought about and consciously acted in ways to rectify their situations when they could have not acted at all. They could have let their situations dictate outcomes, but that is not what consumers did. Three themes emerged as strategies consumers employed to be responsible for their health: being a good patient, politicizing needs, and empowerment.

#### *Being a Good Patient*

When talking about his experience going to the hospital when he was first diagnosed with metastatic colon cancer, Brian said patients should comply with doctor's orders. He tried his best “to be a good patient,” as he said. He adhered to his doctors' orders and underwent the treatments prescribed to him. Granted, this was a life or death situation for Brian. He could have failed to show up for his chemotherapy treatments, but he did not. He usually drove himself to his treatments or asked his mother to take him when he was too ill. He also relied on his familiarity with the health care setting, procedures and knowledge of disease, to help him through his diagnosis and treatments.

Brian described the patient role in much the same way Talcott Parson's described the “sick role.” Granted the sick role concept is outmoded, it does provide a useful framework for understanding how consumers think of their health care. According to Parsons, people who are sick are not at fault for being ill and are not obliged to perform their normal roles, but they must seek treatment from a doctor, comply with his or her recommendations, and try to get well. Telling consumers to take more personal responsibility is akin to the demands of the sick role. By not properly seeking the right kind of care, e.g., relying on emergency rooms too much, ignoring doctors' advice, or not seeking care at all, consumers were not fulfilling their obligation. However, I did not see this with the consumers I met.

Moreover, in trying to seek the “right care at the right time,” and being a good patient by fulfilling the sick role of seeking treatment, Agnes sought alternative forms of pain treatment for her arthritis and the pain she suffers from hip replacements, but had little success under KanCare. While we sat outside a public library, she explained that she wished she could have sufficient physical therapy to treat her pain, but KanCare limits the number of visits she can make for treatment. She has no shortage of medications, as she explained, but she wanted to explore non-

pharmaceutical methods of care. The current medical model of health emphasizes drugs over other forms of care.

Robert explained that while living in the unhealthy housing in Topeka, he was being admitted to the emergency room on a regular basis. He did not select emergency care over primary or preventative care. His living environment counteracted any effort to remain healthy. However, he did not give up and remain there. He struggled for two years to seek better housing in a less stressful environment. He, like the others, worked to figure out how he could better his health and acted. While trying to be “good patients,” they also tried to be good citizens. While not all the consumers were politically active, two were, and I think it is important to recognize those consumers who did make their troubles public.

#### *Politicization of Needs*

Consumers politicized their needs. In her essay on “needs talk,” Nancy Fraser (1989) argues that people's needs are increasingly becoming matters for private individuals, not publics. Privatization of the welfare state removes needs from the political sphere, inhibiting any sort of public discourse that would advance a collective means for providing health and social care, for instance. Agnes and Michael participated in public events about KanCare in different ways. Agnes attended and participated in discussions at public informational meetings about KanCare, but Michael went a step further and testified before the KanCare legislative oversight committee and wrote letters to public officials about his situation.

Michael 'fought the system' in his effort to be personally responsible for his health care. He found himself in a fight with the state for maintaining care that he needs to remain relatively independent in his own home. With the proposed reductions to his 24/7 care, his wife and children would be expected to take on more of the responsibility of providing care. In response,

Michael participated in legislative hearings, presenting testimony of his own experience under KanCare, citing state officials and news reports on the reasons for KanCare, its cost savings, and proposed benefits to consumers. He was active in other ways.

“I have written more than two dozen news articles and columns, testified at three hearings, built upon a broad coalition of Washington, D.C., civil-rights groups, wrote hundreds of emails and sparked more than 20 newspaper articles, radio spots and TV appearances across Kansas...”

His doctors also wrote letters to state officials, including the governor, on his behalf in attempts to prevent his services from being reduced. He even invited the governor of Kansas to spend a day with him in his home to help care for him, but the governor ignored his request. Through fighting his own battle to preserve the dignity and relative independence that home-based care affords him and his family, Michael brought public attention to and confirmed fears of cuts in services for which many consumer advocates had been expressing great apprehension since the reform was announced.

At least two consumers found value in being involved in public life in some way and used that to make their voices heard. Their “needs talk” was a way for them to make their private troubles public. Being responsible for their care involved transforming a personal trouble into a social issue. They were being responsible in a civic sense, not just a utilitarian or consumerist sense of doing things specifically for their health in isolation from other aspects of their lives.

### *Empowerment*

Despite efforts to politicize their needs, consumers did not feel empowered in their lives to meet their own needs. The issue of empowerment actually came up in my conversation with Agnes who indicated she did not feel empowered by KanCare. That prompted me to ask about that in future interviews. I asked consumers if they felt empowered to deal with the challenges

they face in health care, and they all responded “no.” Nevertheless, what I observed in their stories were individuals who tried to find ways to lift themselves up in different ways to meet the challenges they face despite not feeling empowered by KanCare. Agnes sought physical therapy so that she could be more mobile, Brian would try his best to drive himself to his chemotherapy sessions, Sarah started her own business, and Robert enjoyed writing poetry. Michael used his ability to connect with activist publics to advance his interest in, not only bettering his situation, but helping others by trying to influence policy, despite the fact that he could not work any longer. They each employed strategies to better their situations in their own unique ways, strategies I call 'empowerment.' I take the term empowerment from how Agnes described KanCare.

Agnes: My advice for people is to do research. Sunflower says that some people don't like using computers. It's all about empowerment. So you could work solely online or with someone in person. I need both. My pain doctor and orthopedic surgeon pressured me to get Sunflower and they even sent me the application. I tried to do the research. My advice is to call them on the phone, and talk to all three companies. They all have voicemails. The menus are different. The best thing to do is by calling or do your research online.

Kevin: Do you feel that Sunflower is empowering you to be more responsible?

Agnes: This guy [with Sunflower] says, 'We're here to empower you to make a choice.' He says that 'you are supposed to stay out of the provider business, you need to let the provider do their job.' But the provider is not doing their job. If you don't sit on them, they'll just dump you. I have to fight all the time just to keep from being dumped out of care. It was the same under the old system.

Agnes was talking about her frustrations with her MCO when she called in about a claim that had been denied. She explained that the customer service representative or her case manager told her that it was not her place to drive the denial appeals process but was her health care provider's job. She was not satisfied with that response. She felt that if she did not act, she would not receive the care she needed. Indeed, when I asked her to elaborate on this, she said that “personal responsibility means taking an active role in your health care so you don't get taken

advantage of.” Part of this active role taking entailed her researching the three health plans under KanCare and making a decision accordingly. She kept detailed records of all her correspondence with her MCO and doctors. In fact, she brought with her to the interview giant three-ring binders full of forms, letters, statements and the like related to her health care. She also called her MCO frequently to discuss her care to the point that she felt like they probably thought she was being a nuisance.

For a consumer to be empowered, Elbin and Schlesinger (2009: 648) argue one must have “access to independent sources of information, a willingness to take an active role in choosing treatment, and the opportunity to exercise either exit or voice,” in terms of leaving a health plan or making a complaint to the insurance company. They also contend that to be empowered means to know who is to blame for your health problem, and in the case of their study, individuals who held their insurance plan accountable were considered to be empowered. Agnes would have fit their criteria for being empowered, as would others such as Michael and Brian. They are not unlike other consumers in the private insurance market who have the capacity to act on their health needs. As Agnes demonstrates, she takes action when her needs are not being met and does not simply wait around to see if things change.

There was little evidence in their stories of a defeatist mentality, as the 'culture of poverty' thesis might suggest. Although Robert's perspective often was apathy and retreat, that had more to do with his mental health than a loss of values or a learned helplessness. Instead, consumers struggled to challenge the obstacles in their lives through empowering strategies that helped them to improve their situations, whether it was their health plan, their housing, or their finances. Based on these consumers' stories, it would be incorrect to assume that everyone living in poverty simply sit back and accept their circumstances, as the stereotype might lead some to

believe. It is more constructive to focus on both their disadvantages *and* the ways in which they struggle to overcome them, which also challenges stereotypes of the poor.

From their strategies, something I did not expect emerged. Consumers' strategies of empowerment, politicizing needs, and being a good patient demonstrate "personal agency in the stress process model." Thoits (2006: 309) argued that "problem-solving efforts and purposeful acts" allow people to mitigate stressors in their lives. She observed in her previous work that people's distress declined after they sought ways to resolve stress-inducing life situations, something she admits to systematically overlooking by focusing solely on social factors (2006: 310). Like her research subjects, all in all, each consumer I interviewed believed that they were doing all they could for their health and wellbeing despite the constraints of their lives and their respective illnesses or disabilities. They struggled to be responsible people, whether it was being a good patient, politicizing their needs, or empowering themselves. Thoits never used the word "struggle" in her characterization of the agency she observed, but in the case of these consumers, this word is apropos because of their situation. The strategies these consumers used to overcome the obstacles they face was part of their experience of dependency. With poverty, illness and disability also comes being dependent on the state or others, but for them, their dependency was neither desirable nor deterministic. Their dependency was an agentic struggle in which consumers, as active agents and not passive recipients of public assistance, used strategies to combat dependency, a conceptualization that adds substance to what Thoits (2006) observed.

#### *Dependency as Agentic Struggle*

As consumers struggled to make sense of the challenges in their lives and employ strategies to overcome them to improve their circumstances and their health, they all recognized that they were at the same time dependent. Consumers relied on the state, community

organizations, or family for meeting basic needs. It was a situation they were not at all happy with, especially since individualism and independence are important values in American society.

“Yeah, dependency is real ... bad. It's kind of bad ... I don't like being dependent.”

Robert feels guilty for being a “drag on the economy,” as he put it. This was the general sentiment conveyed by consumers. They did not like being dependent on a system that, to them, felt constraining and stifling. They simply wanted to be independent like everyone else. Robert said he “feels like a beggar.” “I am dependent on people who are not nice to me.”

I was on Medicaid from 1984 to 1997. Found out I had an inheritance, so they kicked me off of Medicaid. I went back [on Medicaid] in 2002. Between the time when I ran out of money and got on SSI, it was scary, I could have been out on the street. Some people put me up. That was nice of them. It's a very bad feeling of being thrown out. Dependency is a really bad trip. I'm dependent and it's awful. In some ways, I would like to have a little apartment, not in concentration like here, but I can't do it anymore. I don't have the money, cost of living is going up.

He, like the other consumers, needs help with housing, transportation, food, and health care that he is unable to provide himself adequately due to a lack of resources. Consumers' lives, thus, are tied to the productivity of others in the labor market vis-à-vis taxation or on the charity of others, sometimes from those who express ill will, and it does not feel good. As Robert considered, “What am I free to do? That's very small. Gives you a bad feeling”

Brian, too, valued his independence and subscribed to the American creed of self-reliance. “I don't want to be dependent on the government. I want to take care of myself.” At the same time though, he knows that he cannot do so because of his illness, which was a contradiction he felt but dealt with as best he could. “I have no savings or any income. I got a bill for \$250,000, but there was no way I could pay it. So I had to sign up for Medicaid.” He went to college, majored in a field that pays well, and wants a career. His student health insurance company, which denied him coverage, undermined his ability to take care of himself.



Moreover, the medical bills forced his hand to accept assistance, but he was resilient in his effort to maintain independence despite his illness.

Originally, I had an infection in my system, and that is what got me sick enough to go to the ER. I had been sick for a while, but thought I was developing Crohns. I'm like, 'well, I'll get done with school, I don't have time right now, but I'll figure it out, because the symptoms of Crohn's is the same as colon cancer.' 'I don't have colon cancer, it's probably just Crohn's.'

'Welfare medicine,' as Medicaid is sometimes characterized, often comes with a stigma, but, arguably, Medicaid managed care functions to 'mainstream' Medicaid populations into private sector-like health insurance in which they can be consumers in health insurance markets and not recipients who are dependent on the government. Nevertheless, being a Medicaid consumer is still a form of dependency in the eyes of consumers. It is a dependency they do not like, as it has negative connotations in American society, while independence is valorized. Quoting Daniel Patrick Moynihan, "[dependency] is an incomplete state in life: normal in the child, abnormal in the adult. In a world where completed men and women stand on their own feet, persons who are dependent – as the buried imagery of the word denotes – hang" (Fraser and Gordon 1994: 309).

Nancy Fraser and Linda Gordon (1994) interrogated this discourse of public assistance dependency and why policies to mitigate inequality and poverty are framed in those terms. They argued that the very way we talk about our social worlds serves as sites of struggles to interpret them, and as such, have power over us. The assumptions embedded in such "keywords," such as dependency, are taken-for-granted as true and shape our understanding of our milieu or the milieus of others. Dependency is a deviant condition, stigmatized, sometimes shameful, immoral, and antithetical to citizenship (1994: 315). Being dependent is akin to being a pauper, childlike,

and feminized in terms of being a parasite on independent working men (1994: 316-318). It takes on a moral character.

Dependency is a site of struggle for consumers to make sense of their lives, to be active agents in their care, and it is within that struggle that they establish parameters to their dependency. Compounding their struggle, though, are the important social relations often missing in their lives. At the same time, they employed strategies to challenge their dependency and the power it has over them. How these consumers dealt with their circumstances illustrates Fraser and Gordon's critique of the dependency idea as innately a situation of immorality and deviance. Instead, these consumers *in spite of their dependency* employ strategies of being a good patient, politicizing their needs, and empowering themselves to better their situations while struggling against poor housing, lack of income, and social isolation. This, in turn, serves to challenge stereotypes of the poor.

#### *Challenge to Poverty Stereotype*

Even with her functional, financial, and mobility limitations, Sarah does not want to just sit back and “collect a check.” She started a small business in her effort to be personally responsible. ““Why do you try so hard,”” said one of the other female residents to Sarah. ““Just watch TV and get your check,”” she said. Sarah explained that her neighbor is a drug addict. The young woman calls 911 frequently and disturbs the other residents. She will walk off to the store alone at night, even though the neighborhood is unsafe. Actually, before the interview began, Denise and Sarah started talking about this particular resident, which illustrates a challenge to stereotypes of the poor and how the poor may sometimes view others living in poverty.

Denise - Did you call 911 last night?

Sarah – No, that was the neighbor. I heard what was going on in the hallway. This poor person has seizures, and everybody knows she has seizures. Why she calls 911 in the middle of the night, why she calls them to tell them she has a seizure. I mean, there is no

point to it. They are not going to do anything, because that is part of her everyday life. Yet we cannot get her to not do that. She has been told so many times by them and us, 'honey, we all know you have a seizure disorder.' I think what she is wanting ... I think, her grandmother that passed away a few years ago must have come and consoled her every time she had a big seizure. She doesn't have that now. You aren't going to get that when you live independently. So she calls 911 instead, and we're paying for that. Taxpayers - I pay taxes like everybody else does.

The lazy drug-abuser that refuses to try is a stereotype that obfuscates the complexity of consumers' lived experiences. However, people living in poverty will often accept stereotypes of the undeserving poor when characterizing others who are poor while they at the same time exclude themselves (Shildrick and MacDonald 2013). The poor themselves have bought into the poverty stereotypes - when explaining other people's poverty, and not their own. These consumers, though, challenge poverty stereotypes, such as the lazy freeloader with poor family values and no work ethic. They take action, despite obstacles and in the face of their own dependency. At the same time, these consumers understood their own struggles as products of circumstances while they would sometimes attribute the poverty of others to their failings. These consumers paid their taxes, followed society's rules, and expected to be treated fairly like everyone else. It is an unreconciled situation they find themselves in, one in which they continuously struggle to live a relatively "normal" life.

## **Conclusion**

The provider and consumer experiences of work transfer shed light on health care devolution under KanCare. Experiences we see in terms of different levels of analysis (e.g., organizational vs. individual) actually have more in common than at first glance. The work transfer concept provided a framework for organizing provider struggles to make KanCare work for their patients and consumer strategies to deal with their health needs within the constraints of poverty and dependency *in spite of* calls for more responsibility on their part. Initially, providers

expressed concerns about being able to provide quality care to their patients and communities while struggling to make the new Medicaid system work. After follow-up interviews two years later, some providers were not quite as concerned and felt that some of the early troubles of implementation were resolved. But they did not resolve themselves. Instead, delayed reimbursements, denied pre-authorizations and claims, consumers directed to the wrong doctor, and confusing red tape from the MCOs – regular complaints by providers initially - were corrected, in part, by providers expending extra resources to ensure their patients received the care they needed. This extra work suggests that the state's effort to reduce cost growth, improve the quality of care and of health outcomes, has been a shift in cost from the state to health care institutions in the form of power struggles, resources stretched thin, loss of local control, and inefficiencies. Through their struggles to care for their patients and communities, these providers helped to make KanCare live up to its potential but at a cost to themselves.

This chapter also explained how the devolution of responsibility central to KanCare does not easily reconcile with how some Medicaid consumers actually live. On the one hand, in each case, consumers were not poor until after the onset of illness or advancement of disability. Their poverty exacerbated their illnesses or negative impacts of functional limitations. On the other hand, these consumers were not the typical Medicaid beneficiary, as they each had college degrees. As fundamental causes theory predicts, people with more resources will mobilize them to improve their health or reduce risk factors for disease. Arguably, this is what these consumers did. They employed strategies, or used their personal agency, to mitigate stressors that negatively impact health in the context of a struggle with dependency, poverty and disability. All the while, KanCare expected these same consumers to be responsible for their health, which, in many ways, they already were, but at the same time did not empower consumers to be more responsible in

ways they said were meaningful to them. Thus, the stories of consumers problematized stereotypes of the poor and people receiving public assistance, and indicated that stigmatizing Medicaid beneficiaries is not in line with what consumers do and what they want out of life. Work transfer will continue to be a problem for consumers, and their health care providers, unless the fundamental assumptions undergirding KanCare change.

## CHAPTER 6

### Conclusion

#### **Introduction**

In this concluding chapter, I summarize the findings of the study, discuss the theoretical implications and the limitations of the research, and offer suggestions for future research. I began this study as an effort to understand the implications of the complete privatization of Medicaid in Kansas, and I set out to learn as much as I could. Early on, I realized that the politics of KanCare were contentious, so it made me wonder, how did KanCare come to be enacted given the conflict around it? To explore this question, I analyzed competing claims of reform proponents and the consumer advocates and legislators critical of KanCare. Based on what I learned in my initial research, I wanted to know, what were the implications of KanCare for consumers and for health care providers that serve Medicaid patients? To explore these questions, I interviewed consumers

and health care providers after KanCare went into effect in 2013. Findings revealed insights into Medicaid reform in practice and raised questions about the politics and problems of work transfer. The study contributes to the stress process model literature in medical sociology, advances a social movements framework for understanding how advocacy organizations shape policy, and it adds analytical depth to the concept of work transfer through its application to KanCare.

The politics and problems of work transfer emerge as the product of three main findings of the study. The first main finding was that a subset of atypical Medicaid beneficiaries employed strategies to meet their health needs in ways that mitigated the negative impact of stressors. In addition, consumer knowledge about KanCare and their health care preferences seemed out of touch with the state's effort to get the word out about KanCare and the new benefits it offers. Consumers' stories thus raise questions about policies that emphasize personal responsibility and consumer choice in a one-size-fits-all approach to health care for the poor. The second main finding was that some health care providers felt they had to take on more administrative work to safeguard the care their patients needed, a cost shift that raises questions about how Medicaid managed care impacts health outcomes, quality of care, and expenditures. The third main finding was that by shaping the political discourse on the location of the responsibility for care, the Kansas Health Consumer Coalition helped secure mechanisms of public accountability that could further democratize health policy in Kansas, but at the same time, their moderate voice may have undermined their potential to challenge health care devolution. In the following section, I discuss the theoretical implications of these findings.

### **Why KanCare?**

KanCare was a way to curb rising health care costs in Kansas by expanding the private sector's participation in Medicaid and emphasizing consumers' responsibility for their own health. It emerged from a broader process of welfare state retrenchment guided by neoliberal principles that began before the conservative Brownback administration came into power in 2011. This does not necessarily explain why KanCare was enacted despite resistance. Before delving into the theoretical issues of work transfer, it is important to consider why KanCare took the shape it did in the first place. Two institutional process may provide some answers.

First is a disconnect between policymakers and the public. Providers thought that the extra work they took on was because policymakers did not consider them a resource for reshaping Medicaid. For example, this is how Rachael understood the evolution of KanCare. "The only positive thing is that something had to change, but there is a disconnect between the state and people on the ground dealing with this every day." Lauren agreed and believed that "the clinical aspect received all the attention [of policymakers], while the administrative aspect did not." This seemed to be evident to providers, given the bureaucratic hurdles they encountered. The perception of some was that publics, at least providers in community health, went unheard. Eric said that "there was no provider input into the administrative side before the rollout" of KanCare. There was a "lack of public engagement." From his, and other providers' points of view, the decision to construct KanCare in the way the state did was decided irrespective of public input, and everything afterward was just a legitimation process. The state "started with the idea and worked backward." Policymakers wanted a completely privatized Medicaid program in which consumers were more accountable, and then tried to figure out how to make that happen and justify it instead of starting with the resources available, i.e., provider expertise and knowledge, and work forward to improve health outcomes and quality of care.

Why policymakers did not take the approach some providers suggested I cannot know from the data, but the second reason for how KanCare emerged as it did might give some clues.

The second reason for work transfer under KanCare is policy diffusion. The idea of risk-based capitated managed care propagated through a network of elite policy organizations and research. Data did inform KanCare, such as the work of Mathematica Policy Research on long term services and supports.<sup>136</sup> Scott, a conservative Republican legislator who was on the Legislative Oversight Committee, cited a couple of studies. One study criticized the fee-for-service system, saying that “the payment method rewarded quantity of care over quality.” He also gave an example of “a study by the Journal of the American Medical Association [that] shows that at an alarmingly low level of individuals on Medicaid receive rates of clinical quality care between 14-20 percent less than privately insured *and* non-insured Americans.” He offered no citations for either, so I could not independently verify them, but I do not want to minimize the significance of that. Furthermore, Medicaid Directors attend all sorts of national meetings with other policy elites. For example, I discussed how one former Medicaid Director attended an ALEC convention and sat in on health policy sessions where conservative-leaning ideas are exchanged. Several policymakers, including the Medicaid Director in Kansas, cited that other states are using capitated risk-based models of managed care. Is that sufficient reason to do the same, and then some? Previous research seems to suggest just that. The state offered no evidence in any of the documents I reviewed for successes or failures of managed care in other states, over time, to produce better health outcomes and quality of care. Indeed, policymakers might share selected success stories from specific states like Arizona whose successes must be understood within certain contexts and constraints but ignore what the majority of scholarly research shows

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<sup>136</sup> I learned of this resource through a conversation with a Kansas health policy insider after I completed data collection (<https://www.mathematica-mpr.com/our-focus-areas/health/long-term-services-and-supports>).



about managed care. Market solutions appear and are shared through these various networks of state officials, think tanks, policy wonks, and interest groups. Ideas for how to organize Medicaid emerge in these environments, which act as echo chambers to an extent (Jasny, Waggle, and Fisher 2015), as policymakers are surrounded with, often times, like-minded people and groups. A more rigorous examination of this policy diffusion process is warranted.

Therefore, I argue that a disconnect between policymakers and publics informed by the diffusion of neoliberal policy ideas resulted in the work transfer consumers and providers experienced in the form KanCare eventually took in 2013. That policymakers may or may not have considered the administrative side to care as some providers stressed could have been due to the hegemony of market-based solutions. If the market has all the innovative solutions, that is, for-profit MCOs, then why listen to community health center directors and individual providers? The administrative apparatus would be worked out according to current business principles in the health insurance industry. If things went south, then the pay-for-performance incentives would encourage MCOs to change their practices. Meanwhile, consumers are being told their health is their responsibility, though that is nothing really new to them, and providers are taking on more work. At the same time, critics of KanCare, specifically KHCC, politicized this work transfer by raising questions about public responsibility and the dominant narrative of proponents. In the process, neoliberalism is challenged and this disconnect softened. In the next two sections, I explain the problems and politics of work transfer.

### **Work Transfer as Material and Rhetoric**

Glazer's idea of work transfer, at least in the context of Medicaid devolution in Kansas, is the processes of material experiences moving from one social space to another and a discursive shift from rhetoric to codified discourse. On the one hand, providers were taking on

more of an administrative burden just to make KanCare work for their patients and for their clinics. KanCare introduced new obstacles to providing care. Some felt that there was a loss of the local – local control over case management, a loss of the personal relationships some providers had developed over the years, and poor communication. The loss was the product of outsourcing case management to the MCOs, thus losing local institutional knowledge that has been key to providing care in some communities. The new red tape introduced by adding a third MCO brought about frustration and dismay for some providers. Eventually, some of these problems subsided, but not before they colored providers' perceptions of the new program. KanCare did nothing to address relevant social issues, such as provider cultural competency, discrimination, and stigma (as it relates to mental health), and provided no real incentives for more providers to accept Medicaid or for current ones to continue accepting it. Some providers identified how the new dental care benefit for adults does not really improve access, though it sounds good in theory, thus highlighting the deficit in oral health expertise in KanCare. Overall, they saw no way that KanCare would improve health outcomes or quality of care in any substantive way, and that it only seemed to put obstacles in the way of providing care and increase work.

On the other hand, some consumers demonstrated how they had to work just to be informed about KanCare and the care they received, to live in a healthy environment, to make a bad place to live home, to make ends meet, and to ensure they continued to receive the care they and their doctors felt they needed. These consumers were not necessarily having to do more work post-KanCare implementation, but KanCare was doing little, in their view, to relieve the stresses they experienced, thus implying that this work is their problem and not that of the state or an MCO. In other words, it's a transfer of work in rhetoric, implying that these strategies

consumers employed is their responsibility and not someone else's, a sentiment now codified in policy, whereas it might have just been a guiding idea or conventional wisdom (e.g., the 'sick role').

Consumers' stories highlight the problem of health in the context of poverty and the inequities of social inclusion they face. Housing and environment were stressors that exacerbated mental and physical health issues for some, while limited work opportunities and income supports left others struggling to meet basic needs. Being estranged from family and feeling alienated from their communities left a few consumers feeling alone and with no one to whom to turn for help. Their dependency on government and on other people was something they did not like. Dependency, for these consumers, was an agentic struggle with the day-to-day problems of poverty, disability, and illness. That is, their personal agency was something upon which they relied and valued even though their capacities and resources were limited. In that struggle, each consumer employed their own strategies to empower themselves to take control of their lives as much as they could, despite their dependency. While some sought to be involved and learn what they could about KanCare as it applied to them, others were overwhelmed and confused by either too much or too little information. How these consumers employed various strategies fly in the face of stereotypes of the poor and people receiving public assistance that assume such individuals are lazy or have learned to be helpless, but also demonstrates the limits of what taking personal responsibility can do.

The strategies these consumers employed do raise a question about the capacities these consumers had for taking responsibility. Their specific circumstances might have been unique. They were more highly educated than the average Medicaid consumer, and could have possessed the cultural capital to necessary to successfully navigate the obstacles of poverty, illness, and

disability. Their education reflects middle class values of self-sufficiency and independence. What this suggests is that work transfer may not be as problematic for well-educated individuals, and that the personal responsibility discourse may be somewhat more appropriate for a particular subset of Medicaid consumers. But for the majority, that remains to be seen.

Previous research typically focuses only on consumer and patient literacy, what factors inform their health decisions, and how well they understand information and available options largely in the absence of what states do to inform consumers other than providing quality report cards and the like. Information and choice are not straightforward issues, though, as interviews with consumers demonstrated. What I learned from consumers about choice exemplifies what a study on the transitions from fee-for-service to managed long-term services and supports in Kansas, New York, and Wisconsin in 2013 found (Saucier, Burwell, and Halperin 2013). Consumers in that study said that continuity of care was not a problem for most, as I too found, but “[s]takeholders across the board agreed that consumers could use more or better information, or the same information provided in a different format or in a more timely way” especially for “hard-to-reach population[s] with traditionally low literacy levels,” so that they can make better informed choices about their care (2013:2). I got the same sense from consumers. A policy emphasizing consumer choice is not enough, unless it is communicated effectively (2013: 26). Indeed, the consumers they surveyed felt largely uninformed, and therefore had little information to guide their choices, if they knew they had a choice at all. While the study was unclear as to why consumers make choices they do, what I gleaned from the consumers I interviewed is that to make a choice, one must first know that choices are available. As far as choice of provider is concerned, depending on one's care needs, a range of providers is available if providers choose to participate in the consumer's plan, as Agnes explained, but for others, such as those with mental

health problems like Robert, or with acute illness like Brian, the same range of choices does not exist or is less meaningful. In other words, there is a real difference between a rhetoric of choice and actual choice in a meaningful, material sense of the word. This raises a fundamental question about health care devolution according to a consumer choice model. Can consumer choice actually improve health outcomes? That is, does work transfer improve health?

In all, work transfer is, in part, the product of policymakers disconnected from those who deal with Medicaid on the ground and a policy diffusion process. The first reason that is based on provider perceptions may have merit, but could also be presumptuous. There were opportunities for public input throughout 2011 and 2012 as I documented earlier, but who is to say if more providers participated anything about KanCare would be different. Some of the biggest problems were bureaucratic in nature, such as delays, billing errors, red tape, confusing communications, etc. MCOs have their own proprietary procedures and organizational processes that may well exist no matter what policymakers or publics want. That is the point of devolution to the private sector. The issue, then, is not so much a disconnect as it is the organizing principle of KanCare: devolution to the private sector. If administration of Medicaid remained completely under the purview of the state, providers would have only one set of processes and one group of people to contact. That alone would reduce the workload and could, in fact, reduce mistakes. Also, policymakers would be able to manage practices without institutional barriers inherent to the market, such as proprietary procedures and computer systems. Yet, by shifting the responsibility of the administrative apparatus to the private sector, some of the costs associated with organizational learning, inefficiencies, and problems of the three MCOs, are born by providers and are revealed in the extra work they described.

The consequences of work transfer stretch beyond troubles experienced by individual providers and consumers, and are in ways unintended. Providers and consumers doing this work, which they cannot effectively avoid, justifies the continued devolution of care under KanCare. Policymakers legitimized KanCare through discourse, but providers and consumers legitimized it through practice. This leads me to the politics of work transfer. If we only consider that work transfer is something imposed on people, then we miss how the actions of providers and consumers, and their advocates, unintentionally legitimize the transfer of work, and ultimately, neoliberal policies themselves, thus placing barriers to challenging neoliberalism. However, the analysis of the politics of KanCare suggests that these unintended barriers might be accompanied by some unintended opportunities to challenge health care devolution and work transfer.

### **The Politics of Work Transfer: Obstacles and Possibilities for Advocacy Organizations**

There were three points of contention throughout KanCare's legitimation process that emerged from analysis of the political discourse between proponents and critics. Proponents and critics disagreed on the need for change, the location of the responsibility of care, and KanCare's initial purported successes. Proponents and critics agreed that change was necessary, but disagreed on why and what direction the change should take. For proponents, rising costs had created a budget crisis that was best addressed by managed care and fostering greater individual responsibility for health and health care decisions. Critics called for more accountability and transparency on the part of the state and more public responsibility beyond the mechanisms of public feedback the state created during the legitimation process. Proponents touted successes immediately after implementation; critics offered a counter narrative. KHCC, for example, expressed a concern for lack of transparency and dwindling state responsibility for consumers. In addition, critics were not opposed to privatization, as long as it helps people and keeps tax

dollars in Kansas. Critics were completely opposed to including persons with intellectual and developmental disabilities, but they constitute a minority of the Medicaid population.

Nevertheless, they all indicated a desire to work with policymakers to help move KanCare forward, which unintentionally legitimized privatization.

Privatization was nothing new in Kansas Medicaid prior to 2013, but the extent to which Medicaid has been privatized since then makes the Kansas case significant. The implementation of managed care policies like KanCare illustrates the trend of continued curtailment of publicly funded social program in the U.S. and is an important site for studying the new politics of the welfare state. The actions of KHCC suggests that retrenchment will not go unchallenged. At the same time, the challenge they presented was complex. I will look to the social movements literature to understand the politics of KanCare as a contentious politics of work transfer that presents limits and possibilities for advocacy organizations to shape health care devolution.

In general, political sociologists agree that social movements can impact policymaking (Burstein 1999; Hill, Leighley, and Hinton-Andersson 1995). By conceptualizing advocacy organizations, which attempt to influence policy, as social movement organizations (Andrews and Edwards 2004; Best 2012), it is possible to use a social movements framework to understand the limits of consumer advocacy in Kansas and the influence KHCC had on KanCare and the future of Medicaid in Kansas. Even though KHCC did not operate at the margins of the political system and did not employ strategies of social protest as movements theorists tend to see as typical of social movement organizations, the social movements framework is appropriate according to Quadagno and McKelvey (2010: 63). They argue that elite organizations acting within formal politics using tactics of lobbying in the consumer-directed health care movement reflect both a range of possibilities for how social movement actors achieve their goals and

similarities to other movement types, such as those involving marginalized groups. The point is to analyze the strategies social movement organizations use and within what contexts, not splitting hairs between the types of organizations and their locations relative to the state and formal political institutions. Like other social movements, they framed messages in specific ways to diagnose problems and present solutions, and they shifted their activities as opportunities changed. As with their work on elite social movements organizations, two research traditions in social movements theory are particularly applicable to KHCC's activism: framing theory and the political process model. I will briefly discuss each to show how KHCC shaped the debate on the responsibility of care in society and opened up opportunities for future claims making on the behalf of Medicaid beneficiaries.

Framing theorists argue that social movement organizations are “signifying agents actively engaged in the production and maintenance of meaning for constituents, antagonists, and bystanders or observers (Benford and Snow 2000: 613). The “signifying work” (2000: 614) of movement actors within “a contest of ideas” (Quadagno and McKelvey 2010: 56) involves the construction of frames. Frames typically consist of a diagnostic frame, which identifies the problem, defines grievances, and distributes blame, and a prognostic frame, which gives a solution to the problem identified (2010: 57). Using the framing concept, the ways in which KHCC talked about the need for change, accountability, and success through the legitimization process constituted how they influenced policy as a social movement organization. KHCC defined the issue of accountability as a problem for the state, not just a problem for consumers as personal responsibility. The specifics of the problem were a lack of accountability and transparency on the part of the state. KHCC felt that the reform process needed to be more open to public influence, that policymakers needed to look to consumers as experts in their own



health, and that Medicaid needed sufficient public oversight. The solution KHCC proposed was for the state to create mechanisms of public responsibility. The state did do that to a degree by providing opportunities for publics to weigh in on the reform process throughout 2011 and 2012. Such opportunities are critical for social movements to have influence on policy. To effect change, social movement actors must have access to policymakers willing to listen. However, public input and feedback does not mean decision makers are listening or engaged in a dialogue that results in policy changes. Therefore, KHCC went further and demanded a KanCare ombudsperson, who could be a voice for consumers, and legislative oversight to hold MCOs and the executive branch accountable. Both demands were met. Granted, there is evidence to suggest that policymakers in 2011 already considered the importance of legislative oversight but were leaving that up to the legislature to make that decision, as Rep. Bob Bethel eventually did. So how much causality can be attributed to KHCC's framing of the problem of accountability is limited. What is evident, and more significant, though, is that KHCC shaped the discourse on the location of the responsibility of care by articulating a competing discourse of accountability in Medicaid that may have future ramifications for health policy.

KHCC shaped the conversation about the location of responsibility of care in society. The emphasis by KanCare proponents on personal responsibility was met by calls by advocates for more accountability on the part of the state. There are two implications of this contentious dialogue. First, KHCC was not saying the state completely abrogated its responsibility by outsourcing Medicaid to the private sector and telling consumers to be more accountable. There were measures to hold MCOs accountable through pay-for-performance and regulations to ensure timely payments, opportunities for public input, and of course, the government was still paying for health care. However, what KHCC did was to offer a discursive challenge to the

hegemonic discourse of neoliberalism. They did not allow proponents to have a monopoly on the idea of responsibility for care in society. As such, shaping the discourse was a power struggle between groups that think the responsibility for care should shift from the state towards the market and individuals, on the one hand, and those who think responsibility for care should be a better balance between the state, market and family on the other. That is, for the former, the state should play less of a role, and for the latter, the state should play a stronger role or at least not reduce its role in the provision of care. KHCC did not say that consumers should not be responsible. Critics tended to assume consumers were already being held responsible and that any additional calls for personal responsibility made little sense. Instead, they sought to codify public responsibility in a way that balances accountability between the public and private spheres.

Second, the fact that the state defined accountability as a problem of personal responsibility opened the door for a counter narrative that frames the problem differently but still in a way that resonates culturally (Benford and Snow 2000: 619; Ferree 2003: 307). The cultural resonance of a frame has two central characteristics. The first is the extent to which the framer is credible (2000: 621). KHCC was likely seen by policymakers as a credible movement actor, given the extent to which it was involved in the public input process, cited in media reports<sup>137</sup>, and in giving testimony to the legislative oversight committee, for example. This was not some fringe group that operated on the margins of the political process, calling for radical ideas. The second is that the frame reconciles with dominant discourses in society, or what Ferree calls “discursive opportunity structures.” These are “institutionally anchored ways of thinking that

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<sup>137</sup> A LexisNexis search of “Kansas Health Consumer Coalition” AND Medicaid OR KanCare produced 18 results, and a similar search that included “consumer advocacy” and “consumer advocate” produced similar results, many of which appeared in the *KHI News Service* publication and other newspapers.

provide a gradient of relative political acceptability to specific packages of ideas” (2003: 309). The notion of personal responsibility proponents espoused is a central idea to the hegemonic discourse of neoliberalism enshrined in policies like KanCare, but one that can be challenged on its own terms. As Ferree suggests, movement actors can appropriate terms and reuse them for their own purposes (2003: 310). Selecting the accountability and transparency language as a way to politicize and reformulate ‘responsibility’ was an interesting move on the part of KHCC, as these, too, are ideas that resonate in American culture. In the case of KanCare, the state did purport a commitment to transparency in the reform process, so in a way, KHCC was holding policymakers to that. In Kansas politics, these are common sentiments expressed by those who challenge the conservatives who have been in power over the last few years, and it seems to have some currency, anecdotally speaking<sup>138</sup>. A more systematic analysis of the accountability and transparency frame in Kansas politics in general is needed here, but KHCC’s use of this frame raises a question. If we think of this frame as an “interpretative package” (2003: 308), or a message that connects a social movement to hegemonic ideas and power struggles over group interests over time, then could using the language of accountability and transparency offer a meaningful challenge to neoliberal-oriented health care devolution? In other words, could advocates deploy this frame and expect some success? Before considering the answer to this question, it is important to note that the shaping of the discourse occurred, in part, because of an

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<sup>138</sup> For example, in 2016, I attended a joint special legislative session over public education funding during which Democrats questioned the means by which the legislature arrived at the funding scheme outlined in the proposed FY 2017 education budget to ensure funding equity under the Kansas Constitution. The budget was crafted in a closed-door meeting, and they criticized the fact that not everyone on the Ways and Means and Appropriations Committees was given a copy of the proposed education bill before the special session met on June 23. One Democrat said the legislature needs to be more transparent and demanded to know who was invited to the closed-door meeting and why. The response by the Senate Republican leadership was to give a partial list of who attended, saying he could not remember who all was there. Another example, in 2015, a group of moderate Republicans and Democrats proposed House Bill 2148, the “Kansas transparency act,” which never made it out of committee, but was intended to bring transparency to legislative meetings by requiring live audio broadcasts ([http://www.kslegislature.org/li/b2015\\_16/measures/documents/hb2148\\_01\\_0000.pdf](http://www.kslegislature.org/li/b2015_16/measures/documents/hb2148_01_0000.pdf)).

opportunity created by the state's personal responsibility frame, or what social movement theorists call political opportunity structures.

The political process model advanced by McAdam (1999) and others places the actions of social movement organizations in a political context. Theorists in this tradition argue that political opportunity structures partly determine success or failure of social movements. Broad changes in the political environment bring about opportunities for insurgency. These opportunity structures reduce the risk of insurgency and increase the cost of opposition to it by those in power. The reason protest movements can, but do not always, succeed at these critical moments is because the power differential between the minority group and the status quo it seeks to challenge is less. True, resources have to be mobilized, but that is not enough for movement success. Power relations must afford the possibility for movement groups to realize their interests. Among the characteristics of political opportunity structures important for movement success, significant for KHCC was the availability of access points to the political system (Quadagno and McKelvey 2010: 53). By framing Medicaid as an issue of consumer responsibility, the state opened the door for consumer advocates to respond in kind and put pressure on the state to make changes. Policymakers could have ignored KHCC's claims, but to be in line with their stated objective of leaving reform open to the public, their hands were tied. Thus, the accountability debate made it possible for KHCC to realize its interest in instituting mechanisms of public responsibility. The end result was the KanCare Ombudsman and Legislative Oversight Committee. I do not claim, though, that these entities were caused by KHCC's advocacy, but to think policymakers implemented these mechanisms on their own accord would be shortsighted.

To answer the question of whether or not deploying the frame of accountability and transparency can secure successes for advocacy organizations is to consider what success means. In the case of KHCC, they did see a few modest successes, such as the Ombudsman and Oversight Committee, but also delaying the inclusion of persons with development and intellectual disabilities on the long term care waiver in managed care for one year and regulations to ensure timely provider payments. These wins are not due entirely to KHCC's efforts, but are informed by them. Moreover, these successes are problematic, as critics claimed. The Ombudsman was not truly independent and was not considered an advocate for consumers. The Legislative Oversight Committee was politically stacked to favor one perspective. All consumers are now in managed care, and providers still complain of delayed payments. The real success is less obvious and likely unintended. Establishing mechanisms of public responsibility created a policy feedback effect that could help advocates in the future in ways that might not be noticeable at first.

The policy feedback effect is that KHCC set the stage for future debates on the location of the responsibility for care in Kansas. The creation of legislative oversight and an ombudsman, which did not exist prior to KanCare, established a new normal. Advocates will expect these entities going forward and will have them at their disposal for future claims making. They will have reason to expect inclusion in policymaking in future reforms. While policy feedback effects might have influenced the emergence of KanCare, given most consumers were under privatized managed care prior to 2013, the same institutional forces that brought devolution might also reign in any further devolution of responsibility. In this sense, KHCC was successful in shaping Medicaid, but perhaps not in the way advocates imagined. Success for political sociologists studying social movements needs to be thought of broadly to include unintended consequences.

The (unintended) success of KHCC sheds light on the limits and possibilities of consumer advocacy in Kansas Medicaid. I will discuss first the possibilities that the policy feedback effect might present followed by limitations KHCC faced in the process of KanCare politics. One possibility is democratizing health policy in Kansas. KHCC's engagement with the state through advisory boards, repeated legislative testimony, and interviews with the media implies a commitment to working with the state to make KanCare work. As such, keeping the state in a sustained dialog on the interests of consumers reflects a commitment to democratic policymaking. They worked to include the voices of the otherwise marginalized in policy implementation. Their position implied compromise, in that they did not reject the idea of privatization but only suggested ways to make sure the system worked for their constituents. KHCC took a moderate approach to KanCare, which is in line with the moderate politics that characterized Kansas historically (Wuthnow 2014). The fact they want to be involved in the policymaking process suggests a desire to have a relationship with those whom they might not share common views. Obviously, they want to accomplish their mission, which is to advocate on the behalf of consumers and their needs, but being involved to that extent is more than simply giving voice. How advocates form these political relationships, how they engage policymakers, and how they determine the nature of the voice they bring to politics needs further exploration. Open deliberation and participation, regardless of actual outcomes, engenders a more inclusive policymaking process and makes a difference in whether or not voices and alternative discourses are heard or action is taken at all (Grogan and Gusmano 2007: 9).

A second possibility is challenging negative outcomes of devolution for democratic policymaking. Privatization is a site of contestation between conflicting views on policy ends (Brodkin and Young 1989: 143), the conflict in this case being between proponents of market

solutions and those who want the state to maintain or to have a stronger role in health care. Shifting the location of the responsibility for care to individuals in market relations involves what Paul Starr refers to as a “reordering of claims.” Needs claims that were made in the public sphere are relegated to the private. Not only that, but knowledge and expertise shifts from existing institutional arrangements, which include state agencies and local non-profits and health care providers, more to markets. In the reordering of claims, privatization inhibits public participation and discussion in policy domains and effectively undermines the notion of public purpose and public service in the provision of care (Starr 1989: 42) or possibly, in a more extreme view, an “eclipse of the public” in general (Holmwood 2013: 185). Locating care in the market essentially depoliticizes needs (Fraser 1989: 298), in the sense that needs are a matter for private market exchange relations and not public institutions. Depoliticization dismantles structures and opportunities for public engagement around a particular problem, which might inhibit efforts to resist policy change or to advance a new policy in response, or may even preclude discussion of alternatives. As far as KanCare politics is concerned, this is not what I observed.

By shaping the debate on accountability and securing mechanisms of public responsibility, KHCC’s work effectively counteracts the trends these scholars claim to be the product of privatization. Their arguments presuppose no countervailing forces, but in the realities of health politics, advocacy organization can, and in the case of KHCC do, offer resistance to any sort of reordering of claims, depoliticization, or eclipse of the public. In fact, KHCC helped to safeguard the needs of consumers as something political through the Ombudsman and legislative oversight, because now they have more tangible social spaces for claims making. KHCC kept devolution of health care politicized by making public the private problems of work

transfer, thus giving voice to the experiences of consumers and providers who are often marginalized in the political process. Therefore, the needs of consumers and providers alike will not go unheard, and they can still have a voice, perhaps even more so, in the policymaking process vis-à-vis advocacy organizations. To ignore advocacy organizations' role in health politics is to overlook a significant potential for challenging outcomes of devolution that marginalize consumers. In other words, the negative implications of neoliberalism for health policy can be opposed.

The politics of KanCare also highlight limitations to consumer advocacy. KHCC's commitment to political moderation legitimized work transfer. Its participation in the formal political mechanisms of reform unintentionally facilitated increased privatization and the problems it brought to providers. Moreover, advocating within the 'consumer' framework constrains advocacy organizations to relations of the market as the organizing idea undergirding policy, granting further legitimacy to the expectations of personal responsibility proponents of KanCare maintained. The assumption is Medicaid beneficiaries 'consume' health care commodities, and are not beneficiaries of a program they are entitled to as a right of citizenship. It is a framework that changes the social relations of the state and citizen from paternalistic to agentic, but only in the sense that citizens are agents in the market, and less so as democratic citizens. So on the one hand, a voice of moderation engenders inclusion but on the other hand, it perpetuates the legitimacy of work transfer. Furthermore, treating beneficiaries as consumers means giving them voice and agency, but doing so as consumers within a market of private needs.

Related to the politics of KanCare is the broader dynamics of right wing and conservative organized interest groups with which KHCC found itself competing for access and expertise.



Groups like ALEC and the Kansas Policy Institute had the ears of policymakers more so than consumer advocates, as evidenced in the sorts of policies emerging from the Brownback administration. These groups have the backing of the billionaire Koch brothers and the like, whereas advocates like KHCC are grassroots, non-profits with limited funds and personnel. KPI has Arthur Laffer, while KHCC has concerned citizens. I do not think that groups like ALEC or KPI influenced the development of KanCare, but that these groups have the attention of policymakers is more suggestive of an ethos common to both than one influencing the other. That is, policymakers in Kansas tend to be more receptive to market-based than to public-based solutions. Therefore, when the conventional wisdom of many policymakers is the virtue of privatization, groups like KHCC encounter an ideological barrier difficult to overcome, even with rhetoric of accountability.

### **Policy Recommendations**

Based on the findings of this exploratory study, several implications emerge that could inform conversations about Medicaid reform. First, policymakers should take seriously the non-health related challenges consumers face, and *how* they face those challenges. That means that policymakers, like health policy researchers, must recognize the structures of inequality in which consumers are embedded (Brady, Fullerton and Cross. 2009: 272). The health decisions some KanCare consumers make must be understood within the 'relational constraints' of their lived environments, exclusion from labor markets, and social isolation to contextualize inequalities. Second, economic resources that are flexible to meet the needs of individuals with complex health problems, social and family relations, and physical environment need to be part of a comprehensive approach to ameliorating the problem of health in the context of poverty. I do not think that Medicaid can do this alone, but the broader regime of health and social care in a state,

for example, could do more to include such factors. According to policymakers, KanCare was supposed to dissolve institutional silos within health care that inhibit effective care management and coordination. Perhaps, the silo barriers that need to be dissolved are those separating different realms of care and social policy. Third, consumers need to be empowered to act, not just through rhetorical expressions of personal responsibility and choice, or simply providing a variety of options. The strategies consumers employ to be independent, and the agency they express to mitigate stressors, should be encouraged and facilitated. Transportation services could be expanded beyond providing a trip to and from a doctor's appointment. City buses and taxis could accept Medicaid so that consumers have more options for connecting to their families and communities. Consumers could benefit from a case manager helping them find a new home instead of relying on limited personal capital. Moreover, consumers should not fear losing a job because of taking too much time off for sickness or needing flexible working hours to accommodate unpredictable health conditions. Health policy needs to work in conjunction with labor policy to ensure proper accommodations. Fourth, publics need a stronger voice in health policy beyond advisory boards and working groups that merely afford opportunities for feedback from a small sample of individuals that have the luxury of time and resources to participate. People's stories need to be heard, perhaps in their own homes, not just in formal institutional settings organized by the state. Their voice needs to include, not just the problems they experience, but how they deal with them, as the current study does. Doing so could temper negative feelings toward reform and the skepticism of critics, and thus make implementation seem a little less harrowing. Not only that, but policymaking can be more inclusive if people are more involved in the actual decisions made that affect them. Lastly, work transfer suggests that how policymakers determine the actual cost of health care needs to be sensitive to any negative

externalities for providers generated by the program design and state politics. Claims of cost savings successes would thus be more transparent, which would live up to demands of KanCare's critics. In May 2016, Kansas lawmakers cut \$56 million from Medicaid, which will result in cuts to provider reimbursements by four-percent and reduce some services and benefits.<sup>139</sup> This action contradicts statements made by KanCare proponents throughout the legitimization process that costs were going to go down without cuts to provider reimbursements or services to consumers.

### **Limitations and Contributions of the Research**

There are several limitations of this research. The first is the small sample size: I interviewed seven consumers, ten providers, and five policymakers. I was initially unable to offer consumers a monetary incentive for participation, but later found that offering \$20 did not yield more interviews. Moreover, the consumers I interviewed were more educated than the general Medicaid population, and more likely to be in poverty because of their sickness or disability. The data gained from consumer interviews were rich, but it is impossible for me to know if other themes might have emerged from a broader sample. I was, however, able to conduct a follow-up interview with four providers in 2015, which enabled me to gather more data on how KanCare was unfolding over time. I felt I reached a plateau with provider interviews. However, a more focused study of providers in community health, mental health, or oral health would have helped uncover issues in those areas of health care that I was unable to adequately address in this study. The policymaker interviews did not generate that much data for understanding KanCare politics, because I did not interview enough people intricately involved in constructing KanCare. Four legislators, three of whom were on the KanCare Oversight

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<sup>139</sup> Hart, Megan. 2016. "Brownback budget cuts include \$56M from KanCare." *KHI News Service*. Retrieved June 9, 2016 (<http://www.khi.org/news/article/brownback-budget-cuts-include-56m-from-medicaid>).

Committee, provided limited insights into health policy. The document analysis yielded much less data than expected. Documents were largely repetitive or they were too idiosyncratic to establish common themes. This could be an artifact of the data itself, or a product of not collecting the right data in the first place.

This study, thus, cannot make broad, generalizable claims. As a qualitative study, however, it can offer thick descriptions of the problems of health and health policy for the poor, address the dynamic process of health care reform, and assess its implications. The research advances the stress process model of health, reveals nuances in how Medicaid consumers make health decisions, demonstrates how managed care impacts health, quality of care and costs via health care providers, and offers insights into how advocacy organizations shape policy through discourse.

The current project speaks to the structural sources of social stress that poor people in need of health care encounter. It especially underscores the inadequacy of health policy to address the social conditions of illness and when illness is a causal factor in a consumer's poverty. These inadequacies, in turn, highlight the agency of the poor by revealing the strategies consumers employed in their own unique ways that were specific to their circumstances to mitigate stressors due to poverty. Personal agency is a variable in the stress process model few researchers have explored in great detail. Thus, this study contributes to the stress process model of health by shedding light on the specifics of how personal agency works to interact with individual and social resources to mediate stress.

The research on consumer choice for Medicaid consumers is rather sparse, because they have not had many choices until recent years. As such, medical sociologists and health policy researchers may be missing nuances in how Medicaid beneficiaries make decisions relative to

the general population. The current study contributes to the health decision making literature by showing how some Medicaid consumers have more proximate concerns that occupy their time than sorting through a voluminous array of information, weighing the pros and cons of a few health plans, or researching value-added services. Medicaid consumers likely have similar health preferences to those of people with private health insurance, but their decisions are informed by limited resources, illness, and disability. Because Medicaid is more than just health insurance, choices must include non-health related issues, such as transportation and in-home care. Moreover, due to the complexities of Medicaid, consumers may simply be unaware of their options or the implications of their choices. Depending on how information is distributed, consumer knowledge can vary, and so the choices consumers make can vary according to the means by which they received information. Letters in the mail are not the same as a phone call or in-person meeting with state officials. Devolution of responsibility places more of the work of health care onto consumers even though health policy does not adequately address fundamental causes of illness or limits to consumer knowledge.

Health policy informs the care an individual receives. The experiences of health care providers with claims, reimbursements, authorizations, and other bureaucratic obstacles under KanCare suggest that the administrative side of providing care is an essential part to understanding how health policy affects not only health outcomes, but also quality of care and costs. If MCOs deny claims, people cannot receive care. If reimbursements are late, then that places strain on limited resources of non-profit providers. If authorizations are complex, then that creates additional bureaucratic hurdles that delay care. However, as this study suggests, providers did not acquiesce to the changes under KanCare but fought them all along the way. When they felt red tape interfered with care, they worked to get around it or change the

processes. The work transfer observed in this study shows how policy can influence the provision of health care, but then how providers with a public service commitment responded to curtail this work transfer reveals that health care providers are an important agent in translating policy into practice for their patients. Thus, this study contributes to the health policy literature by advancing our understanding of the relationship between policy, provision of care, and health, specifically how providers can make problematic policies work to the benefit of the provider and patient. The strategies providers employed to deal with the work transfer and cost shift they experienced under KanCare speak to how managed care impacts health, quality of care, and costs. It is the *how* component that has been missing in the medical sociology literature.

Lastly, this study shows that a small advocacy organization can help to shape policy in a hostile political environment. Other studies that have examined the role of advocacy organizations in Medicaid and health care in general, even those that look at the role from a framing perspective, have not considered how advocates participate in a dialogue with policymakers and then explore the implications of that dialogue. By studying the political discourses around KanCare, this study contributes to the political sociology literature by advancing a social movements framework to theorize how advocacy organizations conceptualized as social movement organizations influence policy. The framing of an issue within the context of specific political and discursive opportunity structures can shape political discourse in a way to influence the structure of policy, even when the organization has few resources and operate within a political environment hostile to consumer advocates that challenge neoliberal policies. Based on these contributions, I will conclude by offering four suggestions for future research.

### **Suggestions for Future Research**

First, as the stress process model indicates, individual-level factors are important to health. This study indicates that education level might be one of those factors. We know that education and health vary positively, but as for how that relationship emerges in the stress process model as it relates to the personal agency component, current research is not clear. A future study could explore the relationship between level of education and strategies consumers employ in their struggles with the day-to-day life of low economic status, disability, and illness. Would consumers who are less educated be less likely to employ strategies of empowerment? Exploring this relationship can reveal ways to empower less educated consumers so that agency is a more meaningful way to mitigate stressors.

Second, another issue to explore further is a problem raised by providers' perceived disconnect between policy and the needs of the poor. If policy does not reflect the realities of many consumers living in poverty, then access might be limited. An example that emerged in this study is adult dental care offered under KanCare. Insufficient dental care over many years leads to more than just a need for a good cleaning. KanCare does not cover more invasive procedures for gum care and deeper cleaning. As Gayle indicated, the policy of adult dental care does not reflect the needs of most of the consumers she encounters, thus requiring her clinic to turn most consumers seeking adult dental care away. A future study should explore the dental care needs of Medicaid consumers in relation to policies for adult dental care to demonstrate their effectiveness for meeting those consumers' needs. In the policy component, researchers need to ask policymakers why the adult dental care policy took the shape it did. Do policymakers understand consumers' oral health needs? Such a project could inform policy design and suggest strategies for consumer advocates and community health care providers who advance oral health causes.

A second problem related to policymaker disconnect is the observation made by one of the Federally Qualified Community Health Center directors, Eric. He noted that KanCare did nothing to improve cultural competency in the health care setting. What Medicaid could do is uncertain. More research is needed on culture and language needs in underserved areas where there is a significant non-English speaking Medicaid population in relation to existing community health resources that serve Medicaid consumers. Exploring the opportunity for public-private partnerships between clinics and MCOs to educate office staff and physicians on cultural needs is one possible avenue. While it is not the same thing, Eric did note that his clinic is collaborating with United Health Care to improve health care access in his community. The organizational ties necessary for this initiative may give insights into how a similar arrangement could be made for issues related to care quality.

Third, neoliberalism relies not just on policymakers to pass market-based reforms or an electorate being receptive to them (as Pierson's new politics implies), but on groups that such policies effect to realign their resources and actions to fit the new institutional framework. Some health care providers helped to make KanCare work so they can care for their patients, but what did that work actually entail? Providers gave me a glimpse into the administrative and business side of care, but more research is needed to determine the specifics. A future study could seek to form a typology of strategies providers use to reconcile difficulties they experience under work transfer. This could shed light on how non-profit community and grassroots providers remain resilient in the face of increasing obstacles to care. Understanding what providers do to make policy work for their patients could help policymakers design programs that empower communities to provide care in ways that are more responsive to local needs and best utilize local resources without uprooting institutions upon which some consumers have come to rely for



years. This research could reveal how small, grassroots organizations that provide care services to Medicaid consumers succeed and can be preserved in a neoliberal environment.

Finally, studies such as this one are ideal for activist research and research that informs public policy. There have been increasing calls for public sociology over the years, and we owe it to the people who share their stories and challenges to try to make a difference. I told research participants that I plan to make the results of my study public, sharing the findings with policymakers and health care advocates in particular. What I did not expect in response was that most everyone I talked to said they hoped that my research could make a positive difference to Kansas Medicaid. Doing public sociology means more than just sharing information with broader publics. It means taking our work to the streets and becoming personally invested in its use. A future project could take a more ethnographic and activist approach to further advance a social movements framework for understanding advocacy organizations. The study would move beyond analyzing public discourse and would study in depth the work of an advocacy organization, people's motivations for being involved, and the goals of the movement. Such research could assess why specific diagnostic and prognostic frames are used, why one protest strategy over another is chosen, and how the organization mobilizes resources. The organization could then rethink its strategies and framing of issues based on what it learns from the research finding. This model could be used for any social movement organization, but for those that focus on influencing specific policies like KanCare, the research is more suited to a public sociology that seeks to have immediate impacts on the people I most want to help – the consumers that offered their time, voice, and desire for change.

## REFERENCES

- Altman, Drew. 2015. "Few Consumers Use Information on Health Provider Quality or Price." *Wall Street Journal*. Retrieved July 12, 2016 (<http://blogs.wsj.com/washwire/2015/04/27/few-consumers-use-information-on-health-provider-quality-or-price/>).
- Andrews, Kenneth T. and Bob Edwards. 2004. "Advocacy Organizations in the U.S. Political Process." *Annual Review of Sociology* 30: 479-506.
- Aneshensel, Carol S. 2005. "Research in Mental Health: Social Etiology versus Social Consequences." *Journal of Health and Social Behavior* 46: 221-228.
- 2009. "Toward Explaining Mental Health Disparities." *Journal of Health and Social Behavior* 50(4): 377-94.
- Armstrong, Elizabeth M., Daniel P. Carpenter, and Marie Hojnacki. 2006. "Whose Deaths Matter? Mortality, Advocacy, and Attention to Disease in the Mass Media." *Journal of Health Politics, Policy and Law* 31(4): 729-72.
- Baker, Kelly and Brenda Beagan. 2014. "Making Assumptions, Making Space: An Anthropological Critique of Cultural Competency and Its Relevance to Queer Patients." *Medical Anthropology Quarterly* 28(4): 578-98.
- Bambra, Clare. 2009. "Welfare State Regimes and the Political Economy of Health." *Humanity and Society* 33(1-2): 99-117.
- Basu, Jayasree, Bernard Friedman, and Helen Burstin. 2006. "Preventable Hospitalization and

- Medicaid Managed Care: Does Race Matter?" *Journal of Health Care for the Poor and Underserved* 17(1): 101-115.
- Bauer, Martin W. 2000. "Classical Content Analysis: A Review." *Qualitative Research with Text, Image and Sound*. Edited by Martin W. Bauer and George Gaskell. Thousand Oaks, CA: Sage.
- Béland, François, Stephen Birch, and Greg Stoddart, 2002. "Unemployment and Health: Contextual-level Influences on the Production of Health in Populations." *Social Science & Medicine* 55(11): 2033-52.
- Benford, Robert D. and David A. Snow. 2000. "Framing Processes and Social Movements: An Overview and Assessment." *Annual Review of Sociology* 26: 611-39.
- Best, Rachel Kahn. 2012. "Disease Politics and Medical Research Funding: Three Ways Advocacy Shapes Policy." *American Sociological Review* 77(5): 780-803.
- Blekesaune, Morten and Jill Quadagno. 2003. "Public Attitudes toward Welfare State Policies: A Comparative Analysis of 24 Nations." *European Sociological Review* 19(5):415-27.
- Block, Fred. 2001. "Introduction." Pg. xviii-xxxviii in *The Great Transformation: The Political and Economic Origins of Our Time*. K. Polanyi. Boston, MA: Beacon Press.
- Brady, David, Andrew S. Fullerton and Jennifer M. Cross. 2009. "Putting Poverty in Political Context: A Multi-Level Analysis of Adult Poverty across 18 Affluent Democracies." *Social Forces* 88(1): 271-99.
- Brenner, Neil, Jamie Peck, and N. I. K. Theodore. 2010. "Variegated Neoliberalization: Geographies, Modalities, Pathways." *Global Networks* 10: 182-222.
- Brodkin, Evelyn Z., and Dennis Young. 1989. "Making Sense of Privatization: What Can We Learn from Economic and Political Analysis?" Pp. 121-156 in *Privatization and the Welfare State*." Ed. by S. Kamerman and A. Kahn, Princeton, NJ: Princeton University Press.
- Brooks, Clem and Jeff Manza. 2006. "Social Policy Responsiveness in Developed Democracies." *American Sociological Review* 71(3): 474-94.
- Brown, Wendy. 2006. "American Nightmare: Neoliberalism, Neoconservatism, and De Democratization." *Political Theory* 34(6): 690-714.
- Brunner, Scott C. and Cori E. Ast. 2013. "Issue Brief: KanCare-MCO Contracts Aim to Achieve Savings and Quality Improvement." *KHI News Service*. Retrieved July 9, 2014 (<http://www.khi.org/news/2013/aug/01/issue-brief-kancare-managed-care-contracts-aim-ach/>).

- Burgard, Sarah A., and Lucie Kalousova. 2015. "Effects of the Great Recession: Health and Well-Being." *Annual Review of Sociology* 41: 181-201.
- Burstein, Paul. 1998. "Bringing the Public Back in: Should Sociologists Consider the Impact of Public Opinion on Public Policy?" *Social Forces* 77(1): 27-62.
- 1999. "Social Movements and Public Policy." Pp. 3-21 in *How Social Movements Matter*, edited by M. Guigni, D. McAdam, and C. Tilly. Minneapolis, MN: University of Minnesota Press.
- Burstein, Paul and April Linton. 2002. "The Impact of Political Parties, Interest Groups and Social Movement organizations on Public Policy: Some Recent Evidence and Theoretical Concerns." *Social Forces* 81(2): 380-408.
- Butler, Sandra Sue, and Stephanie Seguino. 2000. "Working in Coalition." *Journal of Community Practice* 7(4): 1-20.
- Callaghan, Timothy, and Lawrence R. Jacobs. 2016. "Interest Group Conflict over Medicaid Expansion: The Surprising Impact of Public Advocates." *American Journal of Public Health* 106(2): 308-13.
- Campbell, Andrea Louise. 2011. "Policy Feedbacks and the Impact of Policy Designs on Public Opinion." *Journal of Health Politics, Policy and Law* 36(6): 961-73.
- Caswell, Kyle J. and Sharon K. Long. 2015. "The Expanding Role of Managed Care in the Medicaid Program: Implication for Health Care Access, Use, and Expenditures for Nonelderly Adults." *Inquiry* 52: 1-17.
- Cawley, John, Asako S. Moriya, and Kosali Simon. 2015. "The Impact of the Macroeconomy on Health Insurance Coverage: Evidence from The Great Recession." *Health Economics* 24(2): 206-23.
- Chang, Cyril F. and Stephanie C. Steinberg. 2008. "TennCare Timeline: Major Events and Milestones from 1992 to 2009." Methodist LeBonheur Center for Healthcare Economics, the University of Memphis. (<http://healthecon.memphis.edu/>).
- Chaudry, Rosemary V., William P. Brandon, Carolyn R. Thompson, R. Stephen Clayton, and Nancy B. Schoeps. 2003. "Caring for Patients under Medicaid Mandatory Managed Care: Perspectives of Primary Care Physicians." *Qualitative Health Research* 13(1): 37-56.
- Chen, Wenhong. 2013. "The Implications of Social Capital for the Digital Divides in America." *The Information Society* 29: 13-25.
- Conover, Christopher J., Peter J. Rankin, and Frank A. Sloan. 2001. "Effects of Tennessee Medicaid Managed Care on Obstetrical Care and Birth Outcomes." *Journal of Health*

- Politics, Policy, and Law* 26(6): 1291-1324.
- Coughlin, Teresa A., Sharon K. Long, and John A. Graves. 2008. "Does Managed Care Improve Access to Care for Medicaid Beneficiaries with Disabilities? A National Study." *Inquiry* 45: 395-407.
- Coughlin, Teresa A. and Sharon K. Long. 2004. "Moving to Medicaid Managed Care: Lessons from State Experiences under the Section 1115 Waiver Authority." Retrieved March 18, 2014 (<http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Reports/downloads/Coughlin.pdf>).
- Coughlin, Teresa A., Sharon K. Long, Timothy Triplett, Samantha Artiga, Barbara Lyons, R. Paul Duncan, and Allyson G. Hall. 2008. "Florida's Medicaid Reform: Informed Consumer Choice?" *Health Affairs* Web Exclusive: W523-32.
- Cummings, Jason L., and Pamela Braboy Jackson. 2008. "Race, Gender, and SES Disparities in Self-Assessed Health, 1974-2004." *Research on Aging* 30(2): 137-167.
- D'Anna, Laura Hoyt, Ninez A. Ponce, and Judith M. Siegel. 2010. "Racial and Ethnic Health Disparities: Evidence of Discrimination's Effects across the SEP Spectrum." *Ethnicity & Health* 15(2): 121-43.
- Daly, Michael and Liam Delaney. 2013. "The Scarring Effect of Unemployment throughout Adulthood on Psychological Distress at Age 50: Estimates Controlling for Early Adulthood Distress and Childhood Psychological Factors." *Social Science & Medicine* 80: 19-23.
- Davidson. Stephen M. 1997. "Politics Matters! Health Care Policy and the Federal System." *Journal of Health Politics, Policy and Law* 22(3): 879-96.
- DeNavas-Walt, Carmen, Bernadette D. Proctor, and Jessica C. Smith. 2012. "Income, Poverty, and Health Insurance Coverage in the United States: 2011." U.S. Census Bureau, Current Population Reports, P60-243, U.S. Government Printing Office, Washington, DC. Retrieved on April 12, 2013 (<http://www.census.gov/prod/2012pubs/p60-243.pdf>).
- Denzin, Norman K. 2001. *Interpretive Interactionism*. Thousand Oaks, CA: Sage Publications, Inc.
- Derlet, R.W., and A. Ledesma. 1999. "How do Prudent Laypeople Define an Emergency Medical Condition?" *Journal of Emergency Medicine* 17(3): 413-18. (<http://www.ncbi.nlm.nih.gov/pubmed/10338230>)
- Dworsky, Amy and Mark E. Courtney. 2007. "Barriers to Employment among TANF Applicants and their Consequences for Self-Sufficiency." *Families in Society* 88(3):379-89.
- Elbel, Brian and Mark Schlesinger. 2009. "Responsive Consumerism: Empowerment in

- Markets for Health Plans.” *The Milbank Quarterly* 87(3), 633–82.
- Engel, Jonathan. 2006. *Poor People’s Medicine: Medicaid and American Charity Care since 1965*. Durham, NC: Duke University Press.
- Esping-Andersen, Gøsta. 1990. *The Three Worlds of Welfare Capitalism*. Cambridge, UK: Polity Press.
- 2000. The Sustainability of Welfare States into the Twenty-First Century.” *International Journal of Health Services* 30(1): 1–12.
- Evans, Carol J., and Annette C. McGaha. 1998. “A Survey of Mental Health Consumers’ and Family Members’ Involvement in Advocacy.” *Community Mental Health Journal* 34(6): 615-23.
- Exley, Catherine. 2009. “Bridging a Gap: the (Lack of a) Sociology of Oral Health and Healthcare.” *Sociology of Health & Illness* 31(7): 1093–108.
- Ferree, Myra Marx. 2003. “Resonance and Radicalism: Feminist Framing in the Abortion Debates of the United States and Germany.” *American Journal of Sociology* 109(2): 304-44.
- Flores, Glenn, Milagros Abreu, Donglin Sun, and Sandra C. Tomany. 2004. “Urban Parents’ Knowledge and Practices Regarding Managed Care.” *Medical Care* 42(4): 336-45.
- Fraser, Nancy. 1989. “Talking about Needs: Interpretive Contests as Political Conflicts in Welfare-State Societies.” *Ethics* 99(2): 291-313.
- Fraser, Nancy, and Linda Gordon. 1994. “A Genealogy of Dependency: Tracing a Keyword of the U.S. Welfare State.” *Signs* 19(2): 309–36.
- Friedland, Robert B. 2005. “How Medicaid Works.” *Generations* 29(1): 35- 38.
- Fiorillo, Damiano and Fabio Sabatini. 2011. “Quality and Quantity: The Role of Social Interactions in Self-reported Individual Health.” *Social Science & Medicine* 73(11):1644-52.
- Fung, Constance H., Marc N. Elliott, Ron D. Hays, Katherine L. Kahn, David E. Kanouse, Elizabeth A. McGlynn, Mark D. Spranca, and Paul G. Shekelle. 2005. “Patients’ Preferences for Technical versus Interpersonal Quality When Selecting a Primary Care Physician.” *Health Services Research* 40(4): 957-77.
- Garcy, Anthony M. and Denny Vågerö. 2012. The Length of Unemployment Predicts Mortality, Differently in Men and Women, and by Cause of Death: A Six Year Mortality Follow-up of the Swedish 1992–1996 Recession.” *Social Science & Medicine* 74(12): 1911-20.

- Garrett, Bowen and Stephen Zuckerman. 2005. "National Estimates of the Effects of Mandatory Medicaid Managed Care Programs on Health Care Access and Use, 1997-1999." *Medical Care* 43(7): 649-57.
- Giatti, Luana, Sandhi M. Barreto, and Cibele C. César. 2010. "Unemployment and Self-Rated Health: Neighborhood Influence." *Social Science & Medicine* 71(4): 815-23.
- Gilens, Martin. 1995. "Racial Attitudes and Opposition to Welfare." *The Journal of Politics* 5 (4):994-1014.
- Glaser, Barney G. 1965. "The Constant Comparative Method of Qualitative Analysis." *Social Problems* 12(4): 436-45.
- Glazer, Nona Y. 1990. "The Home as Workshop: Women as Amateur Nurses and Medical Care Providers." *Gender and Society* 4(4): 479-99.
- Greene, Jessica, Jan Blustein, and Dahlia Remler. 2005. "The Impact of Medicaid Managed Care on Primary Care Physician Participation in Medicaid." *Medical Care* 43: 911-20.
- Grogan, Colleen M. 1997. "The Medicaid Managed Care Policy Consensus for Welfare Recipients: A Reflection of Traditional Welfare Concerns." *Journal of Health Politics, Policy and Law* 22(3): 815-38.
- Grogan, Colleen M., and Michael K. Gusmano. 2007. *Healthy Voices, Unhealthy Silence: Advocacy and Health Policy for the Poor*. Washington, DC: Georgetown University Press.
- Grogan, Colleen M. and Erik Patashnik. 2003. "Between Welfare Medicine and Mainstream Entitlement: Medicaid at the Political Crossroads." *Journal of Health Politics, Policy and Law* 28(5): 821-58.
- Guo, Jing, R. T. Konetzka and Willard G. Manning. 2015. "The Causal Effects of Home Care Use on Institutional Long-Term Care Utilization and Expenditures." *Health Economics* 24: 4-17.
- Gusmano, Michael K., Mark Schlesinger, and Tracey Thomas. 2002. "Policy Feedbacks and Public Opinion: The Role of Employer Responsibility in Social Policy." *Journal of Health Politics, Policy and Law* 27(5): 731-72.
- Hall, Jean P., Noelle K. Kurth, Suzanne L. Hunt. 2013. "Employment as a Health Determinant for Working-age, Dually-eligible People with Disabilities." *Disability and Health Journal* 6(2): 100-6.
- Hall, Jean P., Noelle K. Kurth, Shawna L.C. Chapman, and Theresa I. Shireman. 2014. "Medicaid Managed Care: Issues for Beneficiaries with Disabilities." *Disability and Health Journal* 1-6.

- Haney, Timothy J. 2013. "Off to Market: Neighborhood and Individual Employment Barriers for Women in 21<sup>st</sup> Century American Cities." *Journal of Urban Affairs* 35(3): 303-25.
- Harris, Cherise A. 2002. "Who Supports Welfare Reform and Why?" *Race, Gender & Class* 9(1): 96.
- Harris, Katherine M. 2003. "How Do Patients Choose Physicians? Evidence from a National Survey of Enrollees in Employment-Related Health Plans." *Health Services Research* 38(2): 711-32.
- Harvey, David. 2011. *A Brief History of Neoliberalism*. New York: Oxford University Press.
- Harvey, Philip. 2008. "Is There a Progressive Alternative to Conservative Welfare Reform?" *Georgetown Journal on Poverty Law & Policy* 15(2):157-208.
- Havighurst, Clark C. 1986. "The Changing Locus of Decision Making in the Health Care Sector." *Journal of Health Politics, Policy, and Law* 11(4): 697-735.
- Haynie, Dana L. and Bridget K. Gorman. 1999. "A Gendered Context of Opportunity: Determinants of Poverty across Urban and Rural Labor Markets." *The Sociological Quarterly* 40(2): 177-97.
- Hennessy, Judith. 2005. "Welfare, Work, and Family Well-Being: A Comparative Analysis of Welfare and Employment Status for Single Female-Headed Families Post-TANF." *Sociological Perspectives* 48: 77-104.
- Henry, Alexis D., Linda Long-Bellil, Jianying Zhang, and Jay Himmelstein. 2011. "Unmet Need for Disability-related Health Care Services and Employment Status among Adults with Disabilities in the Massachusetts Medicaid Program." *Disability and Health Journal* 4(4): 209-18.
- Herd, Pamela. 2005. "Reforming a Breadwinner Welfare State: Gender, Race, Class, and Social Security Reform." *Social Forces* 83(4): 1365-93.
- Herring, Bradley and E. Kathleen Adams. 2008. "Medicaid HMO Penetration and Its Mix: Did Increased Penetration Affect Physician Participation in Urban Markets?" *Health Service Research* 43(1): 363-83.
- 2011. "Using HMOs to Serve the Medicaid Population: What are the Effect on Utilization and Does the Type of HMO Matter?" *Health Economics* 20: 446-60.
- Hibbard, Judith H. and Jacquelyn J. Jewett. 1996. "What Type of Quality Information do Consumers Want in a Health Care Report Card?" *Medical Care Research and Review* 53(1):28-47.



- 1997. “Will Quality Report Cards Help Consumers?” *Health Affairs* 16(3): 218-28.
- Hibbard, Judith H., Jacquelyn J. Jewett, Siegfried Engelmann, and Martin Tusler. 1998. “Can Medicare Beneficiaries Make Informed Choices?” *Health Affairs* 17(6): 181-93.
- Hicks, Alexander, and Duane H. Swank. 1983. “Civil Disorder, Relief Mobilization, and AFDC Caseloads: A Reexamination of the Piven and Cloward Thesis.” *American Journal of Political Science* 27(4): 695–716.
- Hill, Kim Q., Jan E. Leighley and Angela Hinton-Andersson. 1995. “Lower-Class Mobilization and Policy Linkage in the U.S. States.” *American Journal of Political Science* 39(1): 75-86.
- Hill, Shirley A., Mary K. Zimmerman, and Michael Fox. 2002. “Rational Choice in Medicaid Managed Care: A Critique.” *Journal of Poverty* 6(2): 37-59.
- Hill, Terrence D., Catherine E. Ross, and Ronald J. Angel. 2005. “Neighborhood Disorder, Psychophysiological Distress, and Health.” *Journal of Health and Social Behavior* 46(2): 170-86.
- Himmerlfarb, Gurtrude. 1984. *The Idea of Poverty*. New York: Alfred A. Knopf.
- Hodin, Renee Marka. 2013. “The Secret Sauce Is ... Consumer Stakeholder Engagement.” *Generations* 37(2): 88-94.
- Hoffman, Beatrix. 2003. “Health Care Reform and Social Movements in the United States.” *American Journal of Public Health* 93: 75-85.
- Holmes, Seth M. 2012. “The clinical gaze in the practice of migrant health: Mexican migrants in the United States.” *Social Science & Medicine* 74(6): 873-81.
- Holohan, John, and Vicki Chen. 2012. “Changes in Health Insurance Coverage in the Great Recession, 2007–2010.” *Medical Benefits* 29(3): 5-6.
- Holmwood, John. 2013. “Rethinking Moderation in a Pragmatist Frame.” *The Sociological Review* 61:S2: 180-95.
- Hsieh, Hsiu-Fang and Sarah E. Shannon. 2005. “Three Approaches to Qualitative Content Analysis.” *Qualitative Health Research* 15: 1277-88.
- Huppertz, John W. and Jay P. Carlson. 2010. “Consumers' use of HCAHPS Ratings and Word-of-Mouth in Hospital Choice.” *Health Services Research* 45(6): 1602-13.
- Hurley, Robert E. 2007. “Research Driven Medicaid Reform: the Case of Managed Care.” *International Journal of Public Policy* 2(3/4): 249-63.

- Jasny, Lorien, Joseph Waggle and Dana R. Fisher. 2015. "An Empirical Examination of Echo Chambers in US Climate Policy Networks." *Nature Climate Change* 5(8):782-786.
- Jewett, Jacquelyn J. and Judith H. Hibbard. 1996. "Comprehension of Quality Care Indicators: Differences among Privately Insured, Publicly Insured, and Uninsured." *Health Care Financing Review* 18(1): 75-94.
- Jones, Gwyn C., and John E. Crews. 2013. "Health Disparities among Workers and Non-workers with Functional Limitations: Implications for Improving Employment in the United States." *Disability & Rehabilitation* 35(17): 1479-90.
- Kaestner, Robert, Lisa Dubay, and Genevieve Kenney. 2005. "Managed Care and Infant Health: an Evaluation of Medicaid in the US." *Social Science & Medicine* 60: 1815-33.
- Kaiser Health News. 2014. "Medicaid Expansion Boosted Emergency Room Visits In Oregon, Study Finds." Retrieved March 20, 2014 (<http://www.kaiserhealthnews.org/daily-reports/2014/january/03/oregon-study-medicaid-expansion-higher-emergency-visits.aspx>).
- Kaiser Family Foundation. 2008. "2008 Update on Consumers' Views of Patient Safety and Quality Information." Retrieved July 12, 2016 (<http://kff.org/health-reform/poll-finding/2008-update-on-consumers-views-of-patient-2/>).
- 2011. "Trends in the Use of Hospital and Provider Quality Ratings." Kaiser Public Opinion Data Note. Retrieved July 12, 2016 (<https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8184.pdf>).
- 2012. "Medicaid Managed Care: Key Data, Trends, and Issues." Kaiser Commission on Medicaid and the Uninsured. Retrieved July 22, 2015 (<https://kaiserfamilyfoundation.files.wordpress.com/2012/02/8046-02.pdf>).
- 2013. "Medicaid: A Primer 2013." The Kaiser Commission on Medicaid and the Uninsured. Retrieved January 28, 2014 (<http://kaiserfamilyfoundation.files.wordpress.com/2010/06/7334-05.pdf>).
- 2015. "Kaiser Health Tracking Poll: April 2015." Retrieved July 12, 2016 ([http://kff.org/health-reform/poll-finding/kaiser-health-tracking-poll-april-2015/?utm\\_campaign=KFF%3A+2015+April+Tracking+Poll&utm\\_source=hs\\_email&utm\\_medium=email&utm\\_content=17197297&\\_hsenc=p2ANqtzOovNKM2jMiH9HH8U36nKXF\\_501ONu3zo2JB385XONGpitzkhM0L6CTT75PYPcLJ-wKQ3Khf19m874xFDHtCib5fSwMA&\\_hsmi=17197297](http://kff.org/health-reform/poll-finding/kaiser-health-tracking-poll-april-2015/?utm_campaign=KFF%3A+2015+April+Tracking+Poll&utm_source=hs_email&utm_medium=email&utm_content=17197297&_hsenc=p2ANqtzOovNKM2jMiH9HH8U36nKXF_501ONu3zo2JB385XONGpitzkhM0L6CTT75PYPcLJ-wKQ3Khf19m874xFDHtCib5fSwMA&_hsmi=17197297)).
- Kamerman, Sheila B., and Alfred J. Kahn. 1989. "Introduction." Pp. 3-11 in *Privatization and the Welfare State*. Edited by S. Kamerman and A. Kahn, Princeton, NJ: Princeton University Press.

- Kansas Department of Children and Families. 2015. “2260 Drug Testing Requirements Specific to TANF#2260.1.” Kansas Economic and Employment Services Manual. Retrieved June 4, 2015 (<http://content.dcf.ks.gov/ees/keesm/current/keesm2260.htm>).
- Kansas Department of Commerce 2015a. “Work Opportunity Tax Credit.” Retrieved June 4, 2015 (<http://www.kansascommerce.com/index.aspx?NID=261>).
- 2015b. “Accelerating Opportunity Kansas.” Retrieved June 4, 2015 (<http://kansascommerce.com/DocumentCenter/Home/View/1393>).
- Kansas Department of Health and Environment. 2009. “Medicaid Transformation Process—Executive Summary.” Retrieved June 3, 2015 ([http://www.kdheks.gov/hcf/medicaid\\_transformation/download/2008/Chapter%201%20-%20Medicaid%20Transformation%20Process%20-%20Executive%20Summary.pdf](http://www.kdheks.gov/hcf/medicaid_transformation/download/2008/Chapter%201%20-%20Medicaid%20Transformation%20Process%20-%20Executive%20Summary.pdf)).
- 2015. “Program Improvements.” Retrieved June 3, 2015 ([http://www.kdheks.gov/hcf/program\\_improvements/default.htm](http://www.kdheks.gov/hcf/program_improvements/default.htm)).
- Kansas Health Institute. 2012. “KanCare: Key Elements of the Medicaid Managed Care Proposal.” Retrieved November 7, 2013 ([http://media.khi.org/news/documents/2012/04/26/KanCareBrief\\_Final.pdf](http://media.khi.org/news/documents/2012/04/26/KanCareBrief_Final.pdf)).
- Kansas State Department of Education. 2013. “Brief History of the Kansas Public/Private Partnership in Child Welfare.” Retrieved June 4, 2015 ([http://www.ksde.org/Portals/0/SES/SEAC/SEAC-13-14-Report-20130917-CW\\_Contracts.pdf](http://www.ksde.org/Portals/0/SES/SEAC/SEAC-13-14-Report-20130917-CW_Contracts.pdf)).
- Kapp, M.B. 1999. “From Medical Patients to Health Care Consumers: Decisional Capacity and Choices to Purchase Coverage and Services.” *Aging & Mental Health* 1999; 3(4): 294-300.
- Kenney, Genevieve M., Stacey McMorro, Stephen Zuckerman, and Dana E. Goin. 2012. “A Decade of Health Care Access Declines For Adults Holds Implications For Changes In The Affordable Care Act.” *Health Affairs* 31(5): 899-908.
- Kenworthy, Lane. 2009. “Tax Myths.” *Contexts* 8(3): 28-32.
- Kim, ChangHwan and Arthur Sakamoto. 2010. Assessing the Consequences of Declining Unionization and Public-Sector Employment: A Density-Function Decomposition of Rising Inequality From 1983 to 2005. *Work and Occupations* 37: 119-161.
- Kim, Jeounghee. 2009. “Barriers to Work among Poor Families: Health Limitations, Family Structure, and Lack of Job Opportunities.” *Journal of Policy Practice* 8(4):317-34.
- Kitchener, Martin, Terence Ng, Nancy Miller, and Charlene Harrington. 2005. “Medicaid Home and Community-Based Services: National Program Trends.” *Health Affairs* 24(1): 206-12.

- Kolker, Emily S. 2004. "Framing as a Cultural Resource in Health Social Movements: Funding Activism and the Breast Cancer Movement in the US 1990–1993." *Sociology of Health & Illness* 26(6): 820-44.
- Korpi, Walter and Joakim Palme. 1998. "The Paradox of Redistribution and Strategies of Equality: Welfare State Institutions, Inequality, and Poverty in the Western Countries." *American Sociological Review* 63(5):661-87.
- Kronebusch, Karl. 1997. "Medicaid and the Politics of Groups: Recipients, Providers, and Policy Making." *Journal of Health Politics, Policy and Law* 22(3): 839-78.
- Kus, Basak. 2006. Neoliberalism, Institutional Change and the Welfare State: The Case of Britain and France." *International Journal of Comparative Sociology*, 47: 488-525.
- Lamphere, Louise. 2005. "Providers and Staff Respond to Medicaid Managed Care: The Unintended Consequences of Reform in New Mexico." *Medical Anthropology Quarterly*, New Series, 19(1), Medicaid Managed Care: 3-25.
- Latimer, Melissa. 2003. "A Comprehensive Analysis of Sex and Race Inequities in Unemployment Insurance Benefits." *Journal of Sociology & Social Welfare* 30(4): 95-122.
- Lau, Richard R. and Mark Schlesinger. 2005. "Policy Frames, Metaphorical Reasoning, and Support for Public Policies." *Political Psychology* 26(1): 77-114.
- Lavee, Einat and Shira Offer. 2012. "'If You Sit and Cry No One will Help You': Understanding Perceptions of Worthiness and Social Support Relations among Low Income Women under a Neoliberal Discourse." *The Sociological Quarterly* 53(3): 374-93.
- Link, Bruce G., and Jo Phelan. 1995. "Social Conditions as Fundamental Causes of Disease." *Journal of Health and Social Behavior* Extra Issue: 80-94.
- Lobao, Linda, and Gregory Hooks. 2003. "Public Employment, Welfare Transfers, And Economic Well-Being across Local Populations: Does A Lean and Mean Government Benefit The Masses?" *Social Forces* 82(2): 519-56.
- Locher, Julie L., Christine S. Ritchie, David L. Roth, Patricia S. Baker, Eric V. Bodner and Richard M. Allman. 2005. "Social Isolation, Support, and Capital and Nutritional Risk in an Older Sample: Ethnic and Gender Differences." *Social Science & Medicine* 60(4): 747-61.
- López, Leslie. 2005. "De Facto Disentitlement in an Information Economy: Enrollment Issues in Medicaid Managed Care." *Medical Anthropology Quarterly* New Series, 19(1), Medicaid Managed Care: 26-46.

- Lovell, Vicky. 2002. "Constructing Social Citizenship: the Exclusion of African American Women from Unemployment Insurance in the U.S." *Feminist Economics* 8(2): 191-97.
- Lowery, David. 2007. "Why Do Organized Interests Lobby? A Multi-Goal, Multi-Context Theory of Lobbying." *Polity* 39: 29-54.
- Marwell, Nicole P. 2004. "Privatizing the Welfare State: Nonprofit Community-Based Organizations as Political Actors." *American Sociological Review* 69: 265-91.
- Maskovsky, Jeff. "Managing" the Poor: Neoliberalism, Medicaid HMOs and the Triumph of Consumerism among the Poor." *Medical Anthropology* 19: 121-46
- Matthes, Jörg and Matthias Kohring. 2008. "The Content Analysis of Media Frames: Toward Improving Reliability and Validity." *Journal of Communication* 58: 258-79.
- McAdam, Doug. 1999. *Political Process and the Development of Black Insurgency, 1930-1970*. 2nd ed. Chicago: University of Chicago Press.
- McCall, Leslie. 2001. "Sources of Racial Wage Inequality in Metropolitan Labor Markets: Racial, Ethnic, and Gender Differences." *American Sociological Review* 66: 520-41.
- McCammon, Holly J., Courtney Sanders Muse, Harmony D. Newman, and Teresa M. Terrell. 2007. "Movement Framing and Discursive Opportunity Structures: The Political Successes of the U.S. Women's Jury Movements" *American Sociological Review* 72(5): 725-49.
- McCammon, Holly J., Karen E. Campbell, Ellen M. Granberg, Christine Mowery. 2001. "How Movements Win: Gendered Opportunity Structures and U.S. Women's Suffrage Movements, 1866 to 1919." *American Sociological Review* 66(1): 49- 70.
- McNally, David. 2011. *Global Slump: The Economics and Politics of Crisis and Resistance*. Oakland, CA: PM Press.
- Mead, Lawrence. 2014. "The New Politics of the New Poverty." Pp. 89-99, in *The Welfare State Reader*, 3<sup>rd</sup> ed. Edited by C. Pierson, F. G. Castles, and I. K. Naumann. Malden, MA: Polity Press.
- Mechanic, David and Donna D. McAlpine. 2010. "Sociology of Health Care Reform: Building on Research and Analysis to Improve Health Care." *Journal of Health and Social Behavior*, 51: S147-59.
- Meyer, Madonna Harrington. 1994. "Gender, Race, and the Distribution of Social Assistance: Medicaid Use among the Frail Elderly." *Gender and Society* 8(1): 8-28.
- Meyer, Madonna Harrington. 1996. "Making Claims as Workers or Wives: The Distribution of

- Social Security Benefits.” *American Sociological Review* 61(3): 449–65.
- Meyer, Madonna Harrington, Douglas A. Wolf, and Christine L. Himes. 2005. “Linking Benefits to Marital Status: Race and Social Security in the US.” *Feminist Economics* 11(2): 145–62.
- Miller, Edward Allen. 2005. “State Health Policy Making Determinants, Theory, and Methods: a Synthesis.” *Social Science & Medicine* 61: 2639–57.
- 2014. *Block Granting Medicaid: A Model for 21<sup>st</sup> Century Health Reform?* New York, NY: Routledge.
- Miller, Edward Alan, and Jane Banaszak-Holl. 2005. “Cognitive and Normative Determinants of State Policymaking Behavior: Lessons from the Sociological Institutionalism.” *Publius* 35(2): 191–216.
- Miller, Edward Alan, Julia Doherty, and Pamela Nadash. 2013. “Pay for Performance in Five States: Lessons for the Nursing Home Sector.” *Public Administration Review* 73(S1): S15–S16.
- Miller, Edward Alan, and Cynthia Rudder. 2013. “Engaging Consumers in Medicaid Nursing Home Reimbursement Policy: Lessons from New York and Minnesota.” *The Gerontologist* 53(4): 27–40.
- Miller, Edward Allen, and William G. Weissert. 2004. “Managed Care for Medicare-Medicaid Dual Eligibles: Appropriateness, Availability, Payment, and Policy.” *The Journal of Applied Gerontology* 23(4): 333–48.
- Mirvis, David M., Cyril F. Chang, Christopher J. Hall, Gregory T. Zaar, William B. Applegate. 1995. “TennCare—Health System Reform for Tennessee.” *Journal of the American Medical Association* 274 (15): 1235–41.
- Moran, Michael. 1999. *Governing the Health Care State: A Comparative Study of the United Kingdom, the United States, and Germany*. New York, NY: St. Martins Press, Inc.
- Moreno, Lorenzo and Sheila D. Hoag. 2001. “Covering the Uninsured through TennCare: Does It Make A Difference?” *Health Affairs* 20(1): 231–39.
- Morgan, Kimberly J., and Andrea Louise Campbell. 2011. *The Delegated Welfare State: Medicare, Markets, and the Governance of Social Policy*. New York, NY: Oxford University Press.
- Morgen, Sandra, Joan Acker, and Jill Weigt. 2010. *Stretched Thin: Poor Families, Welfare Work, and Welfare Reform*. Ithica, NY: Cornell University Press.
- Murray, Charles. 2014. “The two Wars against Poverty.” Pp. 78–88, in *The Welfare State*

- Reader*, 3<sup>rd</sup> ed. Edited by C. Pierson, F. G. Castles, and I. K. Naumann. Malden, MA: Polity Press.
- Myles, John, and Jill Quadagno. 2000. "Envisioning a Third Way: the Welfare State in the Twenty-first Century." *Contemporary Sociology* 29(1): 156-67.
- Nack, David. 2006. "Taking It to the States: The Wisconsin Labor Initiative on Health Care." *Labor Studies Journal* 31: 5-24.
- Nelson, Nancy L. 2005. "Ideologies of Aid, Practices of Power: Lessons for Medicaid Managed Care." *Medical Anthropology Quarterly*, New Series 19(1), Medicaid Managed Care: 103-22.
- National Center for Health Statistics. 2013. "Health, United States, 2012: With Special Feature on Emergency Care." Retrieved March 20, 2014 (<http://www.ncbi.nlm.nih.gov/books/NBK148933/>)
- Oates, Wallace E. 1999. "An Essay on Fiscal Federalism." *Journal of Economic Literature* 37 (3): 1120-49.
- O'Brien, Rourke L. 2013. "Economy and Disability: Labor Market Conditions and the Disability of Working-age Individuals." *Social Problems* 60 (3): 321-33.
- Oermann, Marilyn H. and Thomas Templin. 2000. "Important Attributes of Quality Health Care: Consumer Perspectives." *Journal of Nursing Scholarship* 32(2): 167-72.
- Office of the Governor. 2011. "Administration Announces Medicaid Reforms." Retrieved March 20, 2013 ([http://www.kancare.ks.gov/download/Medicaid\\_Reform\\_Plan\\_Release.PDF](http://www.kancare.ks.gov/download/Medicaid_Reform_Plan_Release.PDF)).
- Olson, Laura Katz. 2010. *The Politics of Medicaid*. New York: Columbia University Press.
- Orloff, Ann S. and Theda Skocpol. 1984. "Why Not Equal Protection? Explaining the Politics of Public Social Spending in Britain, 1900-1911, and the United States, 1880s-1920." *American Sociological Review* 49: 726-50.
- Paradise, Julia. 2014. "Key Findings on Medicaid Managed Care: Highlights from the Medicaid Managed Care Market Tracker." Keiser Family Foundation. Retrieved July 22, 2015 (<http://kff.org/report-section/key-findings-on-medicaid-managed-care-report/>).
- Pearlin, Leonard I. 1989. "The Sociological Study of Stress." *Journal of Health and Social Behavior* 30: 241-56.
- Peck, Jamie. 2001. *Workfare States*. New York: The Guilford Press.
- Perloff, Richard M., Bette Bonder, George B. Ray, Eileen B. Ray and Laura A. Siminoff. 2006.

- “Doctor-Patient Communication, Cultural Competence, and Minority Health: Theoretical and Empirical Perspectives.” *American Behavioral Scientist* 49(6): 835-52.
- Peters, Ellen, Nathan Dieckmann, Anna Dixon, Judith H. Hibbard, and C. K. Mertz. 2007. “Less Is More in Presenting Quality Information to Consumers.” *Medical Care Research Review* 64: 169-90.
- Peters, Ellen, William Klein, Annette Kaufman, Louise, Meilleur, and Anna Dixon. 2013. “More is Not Always Better: Intuitions about Effective Public Policy Can Lead to Unintended Consequences.” *Social issues and Policy Review* 7(1): 114-48.
- Phelan, Jo, Bruce G. Link, and Parisa Tehranifar. 2010. “Social Conditions and Fundamental Causes of Health Inequalities: Theory, Evidence, and Policy Implications.” *Journal of Health and Social Behavior* 51(S): S28-S40.
- Pierson, Paul. 1996. “The New Politics of the Welfare State.” *World Politics* 48(2): 143-79.
- Pilkaskas, Natasha V., Janet M. Currie, and Irwin Garfinkel. 2012. “The Great Recession, Public Transfers, and Material Hardship.” *Social Service Review* 86 (3): 401–27.
- Pina, Darlene L. 1998. “Medicaid Beneficiaries' Experiences in HMO and Fee-For-Service Health Care.” *Journal of Health Care for the Poor and Underserved* 9(4): 433-48.
- Piven, Francis Fox, and Richard Cloward. 1971. *Regulating the Poor: the Functions of Public Welfare*. New York: Vintage.
- Plehwe, Dieter. 2009. “Introduction.” Pp. 1-42 in *The Road from Mont Pelerin: The Making of the Neoliberal Thought Collective*. Edited by P. Mirowski and D. Plehwe. Cambridge, MA: Harvard University Press.
- Poortinga, Wouter. 2006. “Perceptions of the Environment, Physical Activity, and Obesity.” *Social Science & Medicine* (63)11: 2835-46.
- Pracht, Etienne E. 2007. State Medicaid Managed Care Enrollment: Understanding the Political Calculus That Drives Medicaid Managed Care Reforms.” *Journal of Health Politics, Policy and Law* 32(4): 685-731.
- Prior, Lindsay. 2013. “Documents in Health Research.” Pp. 417-32 in *Qualitative Methods in Health Research*. Edited by I. Bourgeault, R. Dingwell, and R. De Vries. Thousand Oaks, CA: Sage.
- Quadagno, Jill. 2004. “Why the United States Has No National Health Insurance: Stakeholder Mobilization against the Welfare State, 1945-1996.” *Journal of Health & Social Behavior* 45: 25-44.
- 2006. *One Nation Uninsured: Why the U.S. Has No National Health Insurance*. New York:



Oxford University Press.

- 2010. “Institutions, Interest Groups, and Ideology: An Agenda for the Sociology of Health Care Reform.” *Journal of Health and Social Behavior* 51: 125-36.
  - 2011. “The Role of Specific Political Factors Interest-Group Influence on the Patient Protection and Affordability Act of 2010: Winners and Losers in the Health Care Reform Debate.” *Journal of Health Politics, Policy, and Law*, 36(3): 449-53.
- Quadagno, Jill and Brandon McKelvey. 2010. “The Consumer-Directed Health Care Movement: from Social Equity to Free Market Competition.” Pp. 50-63 in *Social Movements and the Transformation of American Health Care*. Eds. J.C. Banaszak-Holl., S. R. Levitsky and M. N. Zald. New York, NY: Oxford University Press.
- Read, Jen'nan Ghazal, and Bridget K. Gorman. 2006. “Gender Inequalities in US Adult Health: The Interplay of Race and Ethnicity.” *Social Science & Medicine* 62(5): 1045-65.
- Reed, W. Robert and Cynthia L. Rogers. 2004. “Tax Cuts and Employment in New Jersey: Lessons from a Regional Analysis.” *Public Finance Review* 32: 269-91.
- Rice, Thomas, Lyle Nelson, and David C. Colby. 1992. “Will Medicare Beneficiaries Switch Physicians? A Test of Economic Competition.” *Journal of Health Politics, Policy, and Law* 17 (1): 3-24.
- Rock, Paul. 2001. “Symbolic Interactionism and Ethnography.” Pp. 26-38 in *Handbook of Ethnography*, edited by P. Atkinson, A. Coffey, S. Delamont, J. Lofland, and L. Lofland. Thousand Oaks, CA: Sage.
- Sandoval, Daniel A., Mark R. Rank, and Thomas A. Hirschl. 2009. “The Increasing Risk of Poverty across the American Life Course.” *Demography* 46(4): 717-37.
- Schmeida, Mary and Ramona McNeal. 2007. “The Telehealth Divide: Disparities in Searching Public Health Information Online.” *Journal of Health Care for the Poor and Underserved* 18(3): 637-47.
- Schoppelrey, Susan L., Marcia Martinez and Soo M. Jang. 2005. “Addressing Substance Abuse among TANF Recipients: Current Issues and Approaches.” *Journal of Human Behavior in the Social Environment* 12(2-3): 111-26
- Scutella, Rosanna and Mark Wooden. 2008. “The Effects of Household Joblessness on Mental Health.” *Social Science & Medicine* 67(1): 88-100.
- Seelye, Katherine Q. 1994. “Lobbyists Are the Loudest In the Health Care Debate.” *New York Times*, August 15. Retrieved October 25, 2016 (<http://www.nytimes.com/1994/08/16/us/health-care-debate-lobbyists-lobbyists-are-loudest-health-care-debate.html>).

- Shildrick, Tracy and Robert MacDonald. 2013. "Poverty Talk: How People Experiencing Poverty Deny their Poverty and Why They Blame 'The Poor.'" *The Sociological Review* 61(2): 285-303.
- Shuai, Xiaobing, and Christine Chmura. 2013. "The Effect of State Corporate Income Tax Rate Cuts on Job Creation." *Business Economics* 48(3): 183-93.
- Simmons, Louise. 2002. "Unions and Welfare Reform: Labor's Stake in The Ongoing Struggle Over The Welfare State." *Labor Studies Journal* 27(2): 65-83.
- Sinaiko, Anna D. 2011. "How Do Quality Information and Cost Affect Patient Choice of Provider in a Tiered Network Setting? Results from a Survey." *Health Services Research* 46(2): 437-56.
- Skocpol, Theda. 1989. "Bringing the State Back In: Strategies of Analysis in Current Research." Pp. 3-37 in *Bringing the State Back In*, edited by P. E. Evans, D. Rueschmeyer, and T. Skocpol. Cambridge: Cambridge University Press.
- 1993. "America's First Social Security System: The Expansion of Benefits for Civil War Veterans." *Political Science Quarterly* 108(1): 85–116.
- 1995. "The Rise and Resounding Demise of the Clinton Plan." *Health Affairs* 14: 66-86.
- Smith, David G., and Judith D Moore. 2010. *Medicaid Politics and Policy*. New Brunswick, NJ: Transaction Publishers.
- Snyder, Laura and Robin Rudowitz. 2016. "Trends in State Medicaid Programs: Looking Back and Looking Ahead." Kaiser Family Foundation. Retrieved July 12, 2016 (<http://kff.org/report-section/trends-in-state-medicaid-programs-section-5-managed-care-and-delivery-system-reform/>).
- Soule, Sarah A., and Yvonne Zylan. 1997. "Runaway Train? The Diffusion of State-level Reform in ADC/AFDC Eligibility Requirements, 1950–1967." *American Journal of Sociology* 103(3): 733–62.
- Sparer, Michael. 2012. "Medicaid Managed Care: Costs, Access and Quality of Care." Robert Wood Johnson Foundation. Retrieved October 11, 2015 (<http://www.rwjf.org/content/dam/farm/reports/reports/2012/rwjf401106>).
- Spitz, Bruce. 2007. "Medicaid Agencies as Managed Care Organizations: An "Actuarially Sound" Solution?" *Journal of Health Politics, Policy and Law* 32(3): 379-413.
- Spranca, Mark, David E. Kanouse, Marc Elliott, Pamela Farley Short, Donna O. Farley, and Ron D. Hays. 2000. "Do Consumer Reports of Health Plan Quality Affect Health Plan Selection?" *Health Services Research* 35(5) Part 1: 933–47.

- Starr, Paul. 1984. *The Social Transformation of American Medicine*. New York: Basic Books, Inc.
- 1989. “The Meaning of Privatization.” Pp. 15-48 in *Privatization and the Welfare State*. Edited by S. Kamerman and A. Kahn, Princeton, NJ: Princeton University Press.
- 2011. *Remedy and Reaction: the Peculiar American Struggle over Health Care Reform*. New Haven, CT: Yale University Press.
- Stockdale, Susan E., Kenneth B. Wells, Lingqi Tang, Thomas R. Belin, Lily Zhang and Cathy D. Sherbourne. 2007. “The Importance of Social Context: Neighborhood Stressors, Stress Buffering Mechanisms, and Alcohol, Drug, and Mental Health Disorders.” *Social Science & Medicine* 65(9): 1867-81.
- Stromwall, Layne K. 2002. “Mental Health Barriers to Employment for TANF Recipients.” *Journal of Poverty* 6(3): 109-20.
- Stuber, Jennifer and Elizabeth Bradley. 2005. “Barriers to Medicaid Enrollment: Who Is at Risk?” *American Journal of Public Health* 95(2): 292-298. Retrieved February 23, 2015 (<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1449169/>).
- Sullivan, Michael K. and Christopher R. Larrison. 2003. “Income Barriers Faced by Individuals in Receipt of Temporary Assistance for Needy Families (TANF).” *Journal of Health & Social Policy* 17(4): 15-35.
- Svallfors, Stefan. 2007. “Introduction.” Pp. 1-29 in *The Political Sociology of the Welfare State: Institutions, Social Cleavages, and Orientations*. Edited by S. Svallfors. Stanford, CA: Stanford University Press.
- Tarrow, Sidney. 1996. “The People's Two Rhythms: Charles Tilly and the Study of Contentious Politics. A Review Article.” *Comparative Studies in Society and History* 38(3): 586-600.
- Tannenbaum, Sandra J. 1995. “Medicaid Eligibility Policy in the 1980s: Medical Utilitarianism and the “Deserving” Poor.” *Journal of Health Politics, Policy and Law* 20(4): 933-54.
- Thoits, Peggy A. 2006. “Personal Agency in the Stress Process.” *Journal of Health and Social Behavior* 47(4): 309-23.
- 2011. “Mechanisms Linking Social Ties and Support to Physical and Mental Health.” *Journal of Health and Social Behavior* 52(2): 145-61.
- Thompson, Frank J. 2011. “The Medicaid Platform: Can the Termites Be Kept at Bay?” *Journal of Health Politics, Policy and Law* 36(3): 549-54.
- Treas, Judith. 1983. “Trickle Down or Transfers? Postwar Determinants of Family Income Inequality.” *American Sociological Review* 48(4): 546-59.

- Turner, R. Jay. 2010. "Understanding Health Disparities: The Promise of the Stress Process Model." Pp. 3-21, in *Advances in the Conceptualization of the Stress Process: Essays in Honor of Leonard I. Pearlin*, Ed. by W. R. Avison, C. S. Aneshensel, S. Schieman, and B. Wheaton, New York: Springer.
- Umberson, Debra and Jennifer Karas Montez. 2010. "Social Relationships and Health: A Flashpoint for Health Policy. *Journal of Health and Social Behavior* 51, Extra Issue: What Do We Know? Key Findings from 50 Years of Medical Sociology: S54-S66.
- U.S. Department of Health and Human Services. 2015. "Welfare Indicators and Risk Factors: Fourteenth Report to Congress." Retrieved October 12, 2015 (<https://aspe.hhs.gov/report/welfare-indicators-and-risk-factors-fourteenth-report-congress>).
- Waitzkin, Howard, Joel Yager, and Richard Santos. 2012. "Advancing the Business Creed? The Framing of Decisions about Public Sector Managed Care." *Sociology of Health & Illness* 34: 31-48.
- Walsh, Michael F., and M. Paula Fitzgerald. 2012. "Health Care Reform through the Eyes of Patients: A Qualitative Look at Medicaid Redesign." *Health Marketing Quarterly* 29(1): 18-34.
- Warren, Carol A. B., and Tracy Xavia Karner. 2010. *Discovering Qualitative Methods*. 2<sup>nd</sup> ed. New York: Oxford University Press.
- Weigt, Jill. 2010. "'I Feel Like It's a Heavier Burden . . .': The Gendered Contours of Heterosexual Partnering after Welfare Reform." *Gender & Society* 24: 565-90.
- West, Darrell M., Diane Heith, and Chris Goodwin. 1996. "Harry and Louise Go to Washington: Political Advertising and Health Care Reform." *Journal of Health Politics, Policy, and Law* 21: 35-68.
- Wexler, Sandra and Rafael J. Engel. 1999. "Historical Trends in State-Level ADC/AFDC Benefits: Living on Less and Less." *Journal of Sociology and Social Welfare* 26(2): 37-62.
- Willging, Cathleen E. 2005. "Power, Blame, and Accountability: Medicaid Managed Care for Mental Health Services in New Mexico." *Medical Anthropology Quarterly* New Series, 19(1), Medicaid Managed Care: 84-102.
- Willging, Cathleen E., Raphael M. Semansky, and Howard Waitzkin. 2003. State Mental Health Policy: New Mexico's Medicaid Managed Care Waiver: Organizing Input from Mental Health Consumers and Advocates." *Psychiatric Services* 54(3): 289-291.
- Willging, Cathleen E., Howard Waitzkin and Ethel Nicdao. 2008. "Medicaid Managed Care for Mental Health Services: The Survival of Safety Net Institutions in Rural Settings."

*Qualitative Health Research* 18: 1231-46.

Wilson-Kovacs, Dana, Michelle K. Ryan, S. Alexander Haslam, and Anna Rabinovich. 2008. "Just Because You Can Get a Wheelchair in the Building Doesn't Necessarily Mean That You Can Still Participate: Barriers to the Career Advancement of Disabled Professionals." *Disability and Society* 23(7): 705-17.

Woolhandler, Stephanie and David Himmelstein. 2011. "Healthcare Reform 2.0." *Social Research* 78(3): 719-730.

Wuthnow, Robert. 2014. *Red State Religion: Faith and Politics in America's Heartland*. Princeton, NJ: Princeton University Press.

Zillien, Nicole and Eszter Hargittai. 2009. "Digital Distinction: Status-Specific Types of Internet Usage." *Social Science Quarterly* 90(2): 274-291.

Zimmerman, Mary K., Tracey A. LaPierre, and Joanna Veazey Brooks. 2016. "Missouri Medicaid Consumer Perspectives Study." Unpublished report prepared for the Health Care Foundation of Greater Kansas City.

#### APPENDIX A

##### Interview schedule for KanCare consumers

Thanks for agreeing to do this interview. I'd like to start by getting a little background information.

- What is your name? \_\_\_\_\_
- How old are you? \_\_\_\_\_
- Gender \_\_\_\_Female \_\_\_\_Male [You'll want to notice, not actually ask this]
- Income range- \_\_\_\_\_
- How far did you go in school? \_\_\_\_\_
- Are you currently employed? \_\_\_\_\_ Yes \_\_\_\_\_ No
  - If yes, what is your occupation? \_\_\_\_\_
  - How many hours do you work each week? \_\_\_\_\_
- Who is your family/household is eligible for Medicaid under KanCare? (List first names, ages)
  - Name \_\_\_\_\_ Age \_\_\_\_\_
  - Name \_\_\_\_\_ Age \_\_\_\_\_
  - Name \_\_\_\_\_ Age \_\_\_\_\_
- How long have you/they been eligible for these benefits? \_\_\_\_\_

I am interested in understanding more about Medicaid, especially your opinion on KanCare, which is a recent reform of Medicaid in Kansas.

01. Are you familiar with "KanCare"? \_\_\_\_\_ Yes \_\_\_\_\_ No

- If yes,
    - How would you describe KanCare?
    - How did you learn about KanCare? (Probes—go to open meetings? Newspapers?)
    - How satisfied were you with the earlier Medicaid program?
    - Why do you think KanCare was implemented?
    - Were you in favor of KanCare? Why?
  - If no,
    - Did you know that Medicaid in Kansas was being changed?
    - How satisfied were/are you with the earlier Medicaid program?
02. Some people say that KanCare will promote more individual responsibility for health care. Can you tell me what that means to you?
03. Some people say that KanCare will improve health care by better coordinating health services. Can you tell me what “care coordination” means to you?
04. Have you had an opportunity to seek medical care under KanCare? (or since XXX date it was enacted)
- If yes, who in the family did you seek care for? How satisfied were you with the care?
    - What, if any, changes did you notice?
    - Has the quality of health services you required changed?
    - Did your doctor/dentist/waiting time/case worker change?
    - Did you experience any difficulties?
  - If no, when you seek care, what changes do you anticipate?

## APPENDIX B

### Semi-structured interview schedule for providers

Thanks for agreeing to talk with me. I'd like to start by getting a little information about you?

- What is your name? \_\_\_\_\_
- Gender: \_\_\_\_\_Female \_\_\_\_\_Male
- Age:\_\_\_\_\_
- What is your position? \_\_\_\_\_
- Approximately how many KanCare clients do you serve? \_\_\_\_\_

I am interested in understanding more about KanCare from your perspective, so I'd like your opinion.

- 01. How would you describe KanCare?
- 02. Where did you get most of your information about KanCare?
- 03. Why was KanCare enacted?
- 04. Do you think it was needed? Why?
- 05. How do you think it will benefit Medicaid clients?
- 06. What are the advantages to you as a provider?

Two things that are often said about KanCare is that it will reduce cost through better coordination of care and expecting more individual responsibility from Medicaid clients. Can you address each one of these?

- 07. What is meant by coordination of care? How do you see this happening under KanCare?  
Are there ways that you, personally, are involved in coordinating care for your patients?
- 08. What is meant by individual responsibility? What do you see being done to make consumers of Medicaid more responsible for their own health?

Now I'd like to ask about your own personal experience with KanCare. How would you describe it?

[Probes: what have been your experiences with customer service representatives? With clients? With providing the needed treatment? With authorization for treatment? What do you like about it? Dislike?]

Finally, I'd like to conclude by asking you to compare it with the "old" Medicaid program. Is KanCare better? How so?

[Probes: Do you see if improving health outcomes? Making access easier for patients? What are your hopes and fears about KanCare?



## APPENDIX C

### Semi-structured interview schedule for policymakers

#### Demographic Information

- Interviewee name:
- Gender: \_\_\_\_ Female \_\_\_\_ Male
- Age: \_\_\_\_\_
- Political Party: \_\_\_\_\_ (I complete this)
- How do you describe yourself, politically: liberal, moderate, conservative, other?  
\_\_\_\_\_
- How long in the Kansas legislature? \_\_\_\_

I am interested in learning more about KanCare from those who supported it and those who did not. So first,

01. Were you in favor of enacting KanCare? Why?
02. What were the problems with the “old” Medicaid system?
03. Can you tell me a little about how the policy evolved? (Who introduced the idea, what were the most compelling arguments for it, why did it pass over opposition)
04. What do you think about the contracting of three for-profit insurance companies to provide care? Does it matter?

I have heard some people discuss the advantages of KanCare in terms of better coordination of care and of placing more individual responsibility on consumers. Can you discuss each of these?

05. What is meant by coordination of care? How does it save money?
06. What is meant by individual responsibility?

What is your opinion of KanCare so far?

07. Has it improved health care to the poor?
08. What has been good/ problematic about the program?
09. What does legislative oversight of KanCare mean?
  - a. Are you on the oversight committee? Can you tell me about it?
  - b. What does the oversight committee do, specifically?
  - c. Does the public have access to the oversight committee, say through testimony, hearings, etc.?
10. What are your hopes and fears about KanCare?

Is there anything else you would like to add? Thanks for your time.

## APPENDIX D

### Document List (62 total)

#### **Consumer Advocates**

1. Big Tent Coalition
2. Interhab
3. Interhab2
4. KAAP\_100713 (2)
5. KABC\_100713 (2)
6. OralHealthKansas\_100713 (2)
7. SelfAdvocateCoalition\_100713 (2)
8. BigTentCoalition\_100713
9. Interhab\_100713
10. KABC\_100713
11. SelfAdvocateCoalition\_100713
12. KAAP\_100713
13. OralHealthKansas\_100713
14. Kansas Health Consumer Coalition (KHCC)
15. "KanCare Pilot Project Raises Concerns"
16. "KanCare Will Begin January 1<sup>st</sup>"
17. "KanCare Oversight Legislation Passes Committees"
18. "KHCC says KanCare proposal moving quickly while many questions are left unanswered"
19. "Legislature Finishes 2012 Session"
20. "KanCare and Consumer Rights"
21. "KanCare Update"
22. KHCC\_testimony\_HCBS\_joint\_committee\_legislative\_oversight\_nov\_8\_2012
23. KHCC\_testimony\_senatepublichealthwelfare\_hearing\_kancare\_oversight\_march\_15\_2013
24. "Legislature Considers KanCare Implications"
25. KHCC\_KanCare\_PositionSummary
26. KHCC\_testimony\_HHS\_KanCare\_March\_2012
27. KHCC\_100713
28. KHCC\_KanCare\_Overview
29. KHCC\_CMS Waiver Process

#### **Provider Advocates**

30. ACMHC\_100713
31. KACIL\_2\_100713
32. KACIL\_100713
33. KHA\_100713
34. KHCA\_2\_100713
35. KHCA-KCAL\_100713
36. KMS\_100713
37. KPA\_100713

- 38. KPhA\_100713
- 39. KPSC\_100713
- 40. LeadingAge\_100713
- 41. NASW\_100713

#### **Individual Advocates**

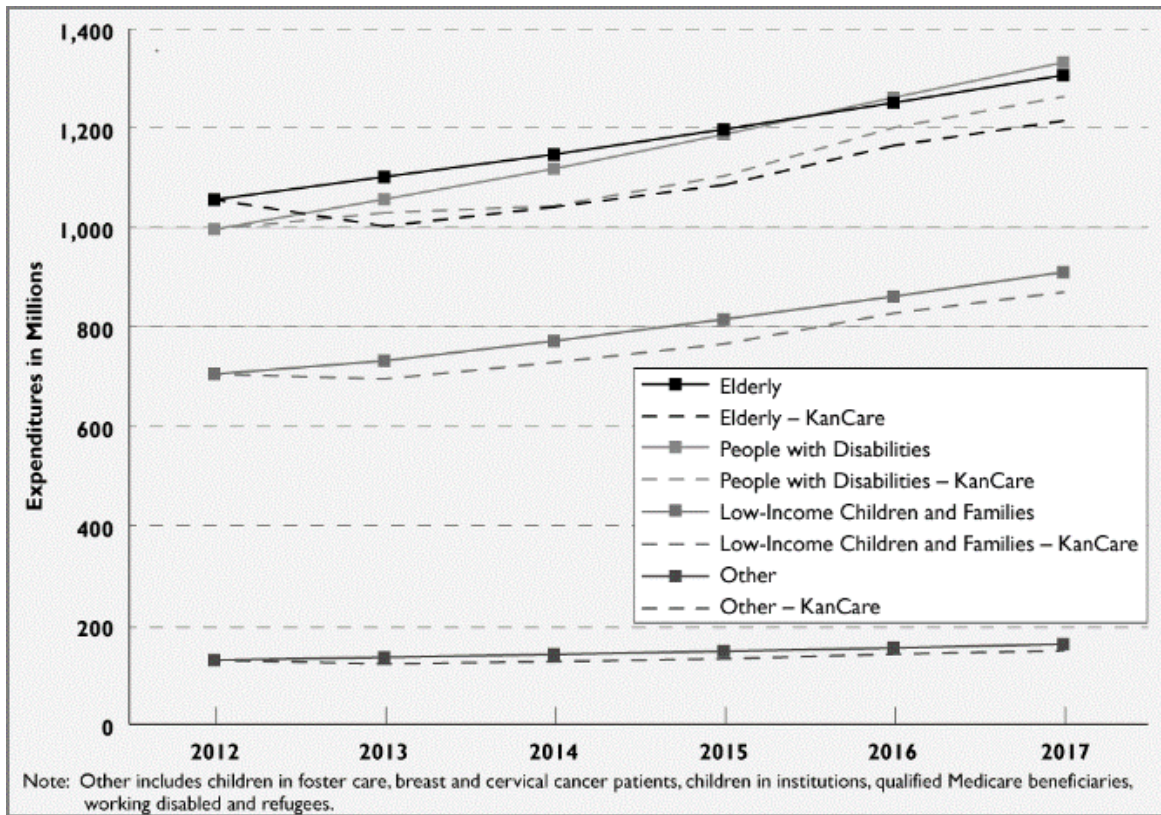
- 42. DelewareHighlandsAsstLiving\_100713
- 43. JENIAN.Inc\_100713
- 44. Wesley\_Galichia\_Wesley\_100713
- 45. Finn\_Bullers\_100713
- 46. Section\_1115\_Public\_Comments emailed to KDHE - KanCare@kdheks.gov, from April 26, 2012 through July 17, 2012

#### **State of Kansas Documents**

- 47. Bart\_Ombudsman\_100713
- 48. KDHE\_3\_100713
- 49. Amerigroup\_2013
- 50. Sunflower\_100713
- 51. UHC\_100713
- 52. Chapter 1 - Medicaid Transformation Process - Executive Summary
- 53. KDADS\_100713
- 54. KDHE\_KanCare-Summary\_100713
- 55. Moser\_KDHE\_100713
- 56. KanCare\_Quarterly\_Report\_QE\_3\_31\_13
- 57. KC-1115Waiver-App\_2012
- 58. 2012 1115 Demonstration waiver application
- 59. "I/DD Waiver Services' Incorporation into KanCare" (KDADS) 1/30/14
- 60. "Amendment to the KanCare Medicaid Section 1115 Demonstration, 11-W-00283/" (KDHE) 8/16/13
- 61. KanCare Quarterly Reports to CMS from March, June, September, December of 2013
- 62. "Fact Sheet: Kansas intellectual/Developmental Disabilities 9I/DD) services under KanCare (KDADS)

## APPENDIX E

Figure 1. KDHE Projections: Annual Costs for Medicaid Population Groups with and Without KanCare



Source: Kansas Department of Health and Environment 1115 Waiver Submission, Budget Neutrality Summary, August 6, 2012. Retrieved November 5, 2015 (<http://www.khi.org/policy/article/issue-brief-kancare-managed-care-contracts-aim-ach>)

## APPENDIX F

Table 1. SES, Social Factors, and Health Indicators for 5 Kansas Counties

	County					Kansas
	Crawford	Douglas	Johnson	Shawnee	Wyandotte	
<b>SES<sup>a</sup></b>						
Median Household Income (\$)	37,378	49,508	74,717	48,451	39,402	51,332
People 25+ with Bachelor's Degree or higher (%)	27.2	49.6	51.7	28.6	15.5	30.3
<b>Social Factors</b>						
Poverty rate (%) <sup>a</sup>	20.6	19	6.5	16.7	23.9	13.7
Unemployment rate (%) <sup>b</sup>	5.2	3.7	3.6	4.6	6.3	4.3
Uninsured Adults (%) <sup>c</sup>	20	17.2	11.9	17.3	27.7	17.5
Severe Housing Problems (%) <sup>d</sup>	17	21.8	11.2	13.9	20.1	13.1
Food Insecurity Rate (%) <sup>e</sup>	17.1	17.2	11.9	15.6	17.9	14.5
<b>Health Indicators</b>						
Life Expectancy (Years) <sup>f</sup>						
Women	78.6	81.7	83	80.4	77.7	80.5
Men	73.2	77.7	79.4	74.7	71.8	75.8
Infant Mortality Rate (deaths per 1,000 live births) <sup>g</sup>	4.7	2.7	4.7	6.8	7.5	6.4
Heart Disease Mortality Rate (per 100,000 population) <sup>h</sup>	216.4	124.8	110.7	160.6	171	156.2
Adults with High Cholesterol (%) <sup>i</sup>	41.1	33	36.3	40.7	37.6	38.1
Adults with Diabetes (%) <sup>i</sup>	13.1	5.4	7.3	10.7	11.6	9.6
Adults with Obesity (%) <sup>i</sup>	34.5	20.3	24.6	33.7	37.1	30
Adults Who Were Ever Diagnosed with a Depressive Disorder (%) <sup>h</sup>	23.9	17.5	15.7	22.3	17.7	18.1

Sources: Data derived from Kansas Health Matters Indicator Comparison Report created July 8, 2015 (<http://www.kansashealthmatters.org/modules.php?op=modload&name=NS-Indicator&file=index&topic=0&topic1=State&topic2=Kansas&breakout=&group=category&regname=Kansas>).

<sup>a</sup> American Community Survey 2009-2013

<sup>b</sup> BLS 03/15

<sup>c</sup> US Census 2013

<sup>d</sup> County Health Rankings '07-11

<sup>e</sup> Feeding America 2013 ([http://www.feedingamerica.org/hunger-in-america/our-research/map-the-meal-gap/2013/KS\\_AllCounties\\_CDs\\_MMG\\_2013.pdf](http://www.feedingamerica.org/hunger-in-america/our-research/map-the-meal-gap/2013/KS_AllCounties_CDs_MMG_2013.pdf)). The rate of percent of population is based on an index derived from Current Population Survey data using the Census Bureau definition of 'food insecure households,' which is "unable, at some time during the year, to provide adequate food for one or more household members due to a lack of resources" ([http://www.census.gov/newsroom/cspan/food\\_security/20121227\\_cspan\\_foodsecurity\\_3.pdf](http://www.census.gov/newsroom/cspan/food_security/20121227_cspan_foodsecurity_3.pdf))

<sup>f</sup> Institute for Health Metrics and Evaluation 2010

<sup>g</sup> KDHE 2009-2013

<sup>h</sup> KDHE 2011-2013

<sup>i</sup> KDHE 2013

Table 2. SocioNeeds Index for 5 Kansas Counties

<b>County</b>	<b>SocioNeeds Index</b>	<b>Ranking</b>
Wyandotte	87.7	5
Crawford	48.3	4
Shawnee	32.4	3
Douglas	12.1	1
Johnson	1.1	1

Source: “The SocioNeeds Index is a measure of socioeconomic need that is correlated with poor health outcomes ... [multiple socioeconomic] indicators were weighted to maximize the correlation of the index with premature death rates and preventable hospitalization rates.” The Index values range from 0-100, by zip code and county, which are then ranked comparatively 1-5, where 1 is least in need and 5 is most in need. Retrieved July 8, 2015 (<http://www.healthychommunitiesinstitute.com/news-release-new-population-health-tool-socioneeds-index/>).

Table 3. Public Program Participation for 5 Kansas Counties

<b>Program</b>	<b>County</b>					<b>Kansas</b>
	<b>Crawford</b>	<b>Douglas</b>	<b>Johnson</b>	<b>Shawnee</b>	<b>Wyandotte</b>	
Kansas Medical Assistance Programs (per 1,000 population) <sup>a</sup>	121.2	55.6	34.8	118.3	145.1	81.2
SNAP Participants (%) <sup>b</sup>	32.5	17.3	22.9	38.7	31.3	n/a
TANF Enrollment as % of population under 18 in 2013 <sup>c</sup>	2.2	2.3	.7	3.7	5.7	2.1

Source: Data derived from Kansas Health Matters Indicator Comparison Report created July 8, 2015

<sup>a</sup> KDHE 2014

<sup>b</sup> USDA 2007

<sup>c</sup> Rate created by dividing the number of children enrolled in TANF (from Kidscount.org) by the total number of population under 18 by county and state (derived from percentage of population under 18 from Kansas Action for Children and total population from the Kansas Division of the Budget, by county and state). Retrieved July 17, 2015 (<http://datacenter.kidscount.org/data/Tables/7895-tanf-benefits?loc=18&loct=5#detailed/5/2832,2836,2859,2902,2918>true/36,868,867,133,38/any/15224>, <http://kac.org/state-and-county-data/>, and [http://budget.ks.gov/files/FY2016/2014\\_Kansas\\_Certified\\_Population\\_7-1-15.pdf](http://budget.ks.gov/files/FY2016/2014_Kansas_Certified_Population_7-1-15.pdf)).